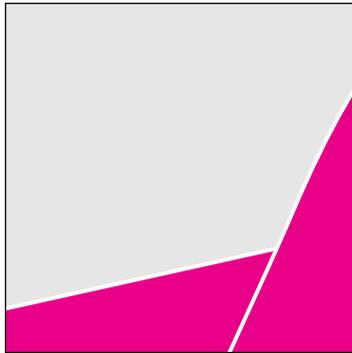


# Uganda: HIV and AIDS-related Discrimination, Stigmatization and Denial



Joint United Nations Programme on HIV/AIDS

**UNAIDS**

UNICEF • UNDP • UNFPA • UNDCP  
UNESCO • WHO • WORLD BANK

UNAIDS Best Practice Collection  
**KEY MATERIAL**

Prepared for UNAIDS  
by

**Sophia Mukasa Monico, Erasmus Otolok Tanga,  
and Augustus Nuwagaba**

The AIDS Support Organization (TASO), Uganda

with

**Peter Aggleton and Paul Tyrer**

Thomas Coram Research Unit  
Institute of Education, University of London, United Kingdom

UNAIDS Responsible Officer – Miriam Maluwa, Law and Human Rights Adviser.

---

UNAIDS/01.43E (English original, August 2001)  
ISBN 92-9173-093-9

---

---

© Joint United Nations Programme on HIV/AIDS (UNAIDS) 2001.

All rights reserved. This document, which is not a formal publication of UNAIDS, may be freely reviewed, quoted, reproduced or translated, in part or in full, provided the source is acknowledged. The document may not be sold or used in conjunction with commercial purposes without prior written approval from UNAIDS (contact: UNAIDS Information Centre).

The views expressed in documents by named authors are solely the responsibility of those authors.

The designations employed and the presentation of the material in this work do not imply the expression of any opinion whatsoever on the part of UNAIDS concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers and boundaries.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by UNAIDS in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

---

UNAIDS – 20 avenue Appia – 1211 Geneva 27 – Switzerland  
Telephone: (+41 22) 791 46 51 – Fax: (+41 22) 791 41 87  
e-mail: [unaids@unaids.org](mailto:unaids@unaids.org) – Internet: <http://www.unaids.org>

# Uganda: HIV and AIDS-related Discrimination, Stigmatization and Denial



Joint United Nations Programme on HIV/AIDS

**UNAIDS**

UNICEF • UNDP • UNFPA • UNDCP  
UNESCO • WHO • WORLD BANK

UNAIDS  
Geneva, Switzerland  
August 2001

## CONTENTS

<b>Acknowledgements</b>	<b>4</b>
<b>Introduction</b>	<b>5</b>
<b>Background</b>	<b>6</b>
HIV/AIDS in Uganda	6
TASO – The AIDS Support Organization	7
HIV/AIDS-related DSD in Uganda	8
<b>The study</b>	<b>10</b>
Research aims and questions	10
Research methodology	11
<b>Findings</b>	<b>12</b>
Forms of HIV/AIDS-related DSD	12
Determinants of HIV/AIDS-related DSD	22
Responses to HIV/AIDS-related DSD	25
<b>Conclusions</b>	<b>28</b>
Recommendations	29
Future Research	30
<b>References</b>	<b>31</b>

## **ACKNOWLEDGEMENTS**

---

Many hearts and minds contributed to this report. To all of them we say thank you.

We are grateful to UNAIDS for providing technical and financial assistance for the project. We are also indebted to Miriam Maluwa, UNAIDS Law and Human Rights Adviser, for her technical input and to Peter Aggleton for his advice throughout the study.

We would like to extend our thanks to our colleagues at TASO for facilitating the smooth execution of the project, and to all those who participated in the research.

Finally, we would like to register our recognition of and great appreciation for the involvement of people living with HIV and AIDS. The hope and actions of these people have gone a long way to demystify AIDS in Uganda and restore the dignity of infected and affected individuals.

SOPHIA MUKASA MONICO  
ERASMUS OTOLOK TANGA  
AUGUSTUS NUWAGABA

## INTRODUCTION

---

This report describes research conducted on issues of HIV/AIDS-related discrimination, stigmatization, and denial (DSD) in central and western Uganda in 1997–98. These issues, regarded by some as the “third epidemic,” have fuelled anxiety and prejudice against those groups most affected by HIV/AIDS.

Despite numerous conferences and expert consultations, and despite the passing of resolutions prohibiting discrimination on the grounds of HIV status, relatively little is known about the causes of these negative responses or how DSD can best be addressed. For this reason, the Joint United Nations Programme on HIV/AIDS provided financial and technical support to researchers from the AIDS Support Organization (TASO) in Uganda in order that insights might be gained into the experiences of Ugandans living with HIV/AIDS, the negative social responses they encounter, and the roots of HIV/AIDS-related DSD.<sup>1</sup>

This report describes the aims, methods, and findings of the research, with a particular emphasis on the forms and determinants of DSD and the responses to it. We are particularly concerned with moving beyond previous research on DSD, which has had a tendency to focus only on individual cases or experiences, or on the role of non-governmental organizations (NGOs) in exerting pressure on governments and national authorities to act to prevent further discrimination. This report, in contrast, aims to offer an account of how DSD operates, and what causes it, in a range of contexts in two contrasting regions. We highlight particular areas of concern and make recommendations to address them, so that efforts can be made to bring HIV/AIDS-related DSD to an end in Uganda. We very much hope that the way these issues have been addressed will be of some benefit to those in neighbouring countries with similar problems.

---

<sup>1</sup> A similar research study, conducted in Mumbai and Bangalore, India, is available as a sister publication to this report. *India: HIV and AIDS-related Discrimination, Stigmatization and Denial*, UNAIDS 2001.

## **BACKGROUND**

---

### HIV/AIDS in Uganda

**A**IDS was first identified in the Rakai District of Uganda in the early 1980s. Since that time, cases of HIV have been reported throughout the country, and the scale of the epidemic has been severe. Of a total population of 22 million people, it is estimated that 1.9 million have been infected with the human immunodeficiency virus (HIV), about 67,000 of them children. Approximately 500,000 people have died of HIV/AIDS-related causes, and 1.7 million children have been orphaned. The statistics further indicate that at least 1.4 million people in the country are presently living with HIV/AIDS.

Recent research also indicates that in urban sentinel sites new infection rates have declined by about 50 per cent. At one urban antenatal clinic, for example, rates dropped from 29.5 per cent in 1992 to 13.4 per cent in 1998, the reduction being predominantly in the 15–19 age range (Uganda Ministry of Health, 1998). There is also evidence of change in sexual behaviour. One study comparing young people's sexual behaviour in 1995 with a similar study from 1989 suggested that first sexual experiences were being delayed for two years. Similarly, reported rates of condom usage suggest a sharp increase (Asiimwe-Okiror et al., 1997). However rates of infection are still high, and there is an ever-increasing need for efforts to sustain and improve AIDS control initiatives.

The impact of AIDS, which has been felt across Uganda, bears both a social and an economic cost. AIDS has reduced the size of the labour force, and the quantity of land under cultivation has diminished. As a consequence, income and food security are threatened for a significant proportion of the population. Cash-crop production has declined – coffee production in northern Uganda is one important example – because work time is spent caring for people with AIDS. A study conducted in the central region (Babikwa and Kirumira, 1993) suggested that, as adult mortality accelerates, the ability of households to cope and even survive will be seriously compromised. Children were felt to be particularly at risk.

One of the first important responses to the AIDS crisis in Uganda was the establishment of the National AIDS Control Programme (NACP) in 1986, coordinated by the Ministry of Health and supported by the World Health Organization's former Global Programme on AIDS. However, the NACP tackled HIV/AIDS mainly from a medical standpoint, and the need to involve other sectors became clear by the early 1990s. Since then, the national response has been a broadly collective one. People with HIV/AIDS, the government, NGOs, religious groups, communities, lawyers, and medical staff have

worked alongside international bodies and donors in responding to the epidemic. This response has been characterized by openness and political support from all levels of government. A particularly important development was the establishment of the Uganda AIDS Commission in 1992. This took a multisectoral approach, involving people with HIV/AIDS, women's groups, NGOs, and lawyers – among other groups – much more centrally than before.

Both the NACP and the AIDS Commission have led a number of key initiatives that have attempted to improve Uganda's response to HIV/AIDS. These have included:

- widespread HIV/AIDS education campaigns
- provision of condoms
- establishment of regional blood transfusion services to screen blood for HIV antibodies
- care for children orphaned by the epidemic
- establishment of AIDS control programmes in 11 line ministries
- provision of drugs to treat opportunistic infections
- involvement in vaccine trials.

Perhaps most importantly, the government has enacted a national multisectoral policy on HIV/AIDS that recognizes the need for collective action against AIDS. This policy stipulates that:

All Ugandans have individual and collective responsibility to be actively involved in AIDS control activities in a coordinated way. The fight against AIDS is not only directed at the prevention of the spread of HIV, but also addresses the active response to and management of all perceived consequences of the epidemic (National HIV/AIDS Strategic Framework, 1998).

## TASO – The AIDS Support Organization

One of the key players in the response to the HIV/AIDS epidemic in Uganda has been the AIDS Support Organization (TASO). In 1986, a small group of individuals and families affected by the epidemic began meeting together to offer mutual support. From there, a core group of 16 people, some with HIV/AIDS, began delivering training in hospitals, working to raise staff awareness and information levels about the needs of people with AIDS. ActionAid sponsored these initial workshops and gave the group start-up funding the following year. In 1987 the group formally took the name TASO and set as its aim the provision of care and support to people with AIDS and their families.

TASO's early successes were such that it received additional and significant funding from the United States Agency for International Development (USAID) in 1988 and 1991 and from the United Kingdom Government in 1990 and 1991. The organiza-

tion was also awarded a prestigious “It Works” award from NORAD in 1990. By this stage, branches of TASO were beginning to open in a number of sites across the country, and in 1992 large numbers of specially trained individuals began to provide counselling services. In addition, the organization expanded its remit in the mid-1990s to cover family planning and services for sexually transmitted diseases (STDs).

Since the first small meeting in 1986, TASO has grown rapidly. It has significantly increased its client base – with approximately 6,000 new clients every year throughout the 1990s – and provides many services. Primary services are as follows:

- counselling for clients and family members
- medical care
- social and financial support (e.g. food, school fees, skills building for income-generating activities)
- AIDS education to raise awareness and decrease stigmatization
- community mobilization to encourage local participation in AIDS care and prevention
- training for AIDS counsellors, community workers, peer educators, and medical staff
- support for local groups involved in AIDS care.

With seven centres across Uganda, the organization continues to play a major role in AIDS care, education, and support. Nonetheless, there are many challenges for the future, including addressing the needs of women more effectively (about two-thirds of the clients are female, their proportion rising steadily through the 1990s), coping with significantly larger numbers of new clients, and maintaining community commitment and involvement.

### HIV/AIDS-related DSD in Uganda

Despite TASO’s efforts and the work of all those involved in HIV issues in Uganda, it was evident in the early to mid-1990s that discrimination, stigmatization, and denial were still very serious problems in the country. Particular negative effects have been identified in “culturally defined outgroups” (Barnett and Blaikie, 1992), among whom HIV and AIDS-related stigma has led to many of those infected and affected withdrawing from social contact with others altogether (Asingwire, 1992). Such people almost inevitably had more difficulty accessing health-promotion activities, the result being poorer mental and physical health for those affected (Rwabukwali, 1992). Other researchers (e.g. Asingwire, 1992; Ankrah et al., 1993) therefore underscored the need to address questions of psycho-social support for people with HIV/AIDS, and the concomitant need to address issues of DSD in all settings where it might be expected to occur.

Earlier research has suggested that Uganda faces a number of particular problems in relation to DSD. First, because of denial, some young people were felt to be

complacent about the risks of HIV transmission and lacked basic information about the epidemic (Nuwagaba, 1994).

Second, particular difficulties were reported in relation to safer sex for married women (Ankrah et al., 1993). Although the majority of married women were aware of HIV transmission issues, they felt unable to control the risk behaviour of their male partners or to negotiate safer sex. Because Ugandan society regards extramarital sex as socially acceptable, it has been difficult historically to promote safer sex among married couples, many of whom (despite having occasional partners) see themselves as 'protected' by the marriage bond.

A third area of concern centred on the attitude of community members. Two studies (Asingwire, 1992; Ankrah et al., 1993) found that community members were sometimes unwilling to provide care and social support to people with AIDS because of fears of HIV transmission, the stigma associated with AIDS, and judgemental attitudes. A further study has reported that, although close neighbours extended assistance, they usually did so only when asked directly (Nuwagaba, 1994).

Fourth, research has identified concerns relating to the attitudes of family members, particularly towards widows of men who have died of AIDS-related conditions (Asingwire, 1992). Ostracization of children and lack of familial care (including being denied food) threatens the survival of widows and their children, particularly in rural communities.

Finally, HIV/AIDS was seen to cause insecurity in employment and discrimination in the workplace. It has been reported that some organizations terminated the contracts of people with AIDS when they become ill (Uganda Ministry of Health, 1995). Those who were HIV-positive and unemployed found it difficult to find work; those who did find work were likely to encounter discrimination because of their HIV status. Considering that almost every household in Uganda has been affected by HIV/AIDS in some way, it may appear surprising that 53.5 per cent of respondents in one study said that people with HIV/AIDS should not be able to work alongside those who were uninfected (Uganda Ministry of Health, 1995).

Challenging these types of discrimination has proved difficult: many Ugandans blamed others for the epidemic rather than addressing issues of prevention. Thus, one research project reported that Tanzanians were scapegoats for bringing AIDS across the border during the liberation war of 1979 (McGrath, 1992). Women, particularly female sex workers, have also been blamed (de Bryn, 1992). Moreover, many communities in Uganda have viewed the epidemic as a disease of rich urbanites and not a concern for rural communities (Ankrah et al., 1993), although more-recent evidence suggests that this situation has changed (Macro International, 1996). Ignoring the existence of HIV and failing to act to prevent the further spread of infection were common forms of denial reported in earlier research (Malcolm, 1994).

## THE STUDY

### Research Aims and Questions

In 1997, the Joint United Nations Programme on HIV/AIDS provided financial and technical support to enable a local research team to investigate further the problems of HIV/AIDS-related DSD in Uganda.<sup>2</sup> The team began by establishing three overarching research aims, supplemented by related research questions.

1. To analyse the different forms of HIV/AIDS-related discrimination, stigmatization, and denial in contrasting sites within Uganda.

*What are the different forms of HIV/AIDS-related DSD in specific study areas? How are these forms defined in various cultural, economic, and social contexts? Do the different stages of the epidemic influence the forms of HIV/AIDS-related DSD? How are these different forms manifested at the individual, family, and policy levels?*

2. To establish which factors influence different forms of HIV/AIDS-related discrimination, stigmatization, and denial.

*What are the origins of HIV/AIDS-related DSD? What are the specific factors responsible for enhancing these forms? What is the relative impact of these factors influencing HIV/AIDS-related DSD? How does the impact of these factors vary across different cultural, social, and economic settings?*

3. To assess the various responses to which HIV/AIDS-related discrimination, stigmatization, and denial give rise.

*What has been the response of people living with HIV/AIDS to DSD? What has been the response of affected families and communities? What has been the response of selected institutions such as education, health care, and employment systems? How has the legal and juridical system addressed issues related to DSD?*

---

<sup>2</sup> The three senior investigators recruited four research assistants from a pool of social science graduates and TASO counsellors in order to be able to conduct the research. All the assistants subsequently received training.

## Research Methodology

In order to explore these questions in contexts relevant to Ugandans, the senior investigators identified two contrasting sites in which to conduct the research: Kampala District in the centre of the country and Mbarara District to the west. Kampala District is the largest urban area in Uganda and takes in the capital city. It is a major centre, with social, professional, welfare, and legal organizations and services active in the struggle against HIV/AIDS. The district contains a heterogeneous population of different cultures, ethnic groups, and ways of life. Mbarara District, in contrast, is rural and relatively homogeneous with respect to culture, behaviours, and perceptions. Far fewer organizations provide HIV/AIDS-related services in this part of the country. It is generally assumed that knowledge of and awareness about HIV/AIDS is lower in Mbarara than in Kampala.

TASO's prior experience providing care and support to people living with HIV/AIDS in both of these sites had suggested that it would be profitable to focus on three contrasting settings within which HIV/AIDS-related DSD might be expected to manifest itself. These are the individual and family setting, the institutional and community setting (including the workplace, health care system, and places of worship), and the policy setting. It should be recognized that these overlap to some extent, and that responses within one setting might be expected to influence those in others.

Researchers conducted an initial "reconnaissance" exercise in both districts to locate particular areas in which the study might be carried out, to establish the household concentration of people living with and affected by HIV/AIDS, and to identify community leaders and obtain their consent for the study. Additionally, researchers aimed to identify local organizations working with, and providing services for, people living with HIV/AIDS.

Eight potential categories of respondents were identified: people living with HIV/AIDS (PLHA), families affected by HIV/AIDS, counsellors, legal professionals, medical personnel, community leaders, religious leaders, NGO workers, and community-based association (CBA) workers. This approach allowed the study to focus on different factors affecting HIV/AIDS-related DSD.

Data were collected through individual interviews, focus group discussions, and observation. In-depth individual interviews were held with 22 people living with HIV/AIDS in Kampala, 20 in Mbarara, and 10 representatives of families affected by HIV/AIDS in each of these locations. Additionally three counsellors, three medical personnel, and two community leaders were interviewed in each site. Also interviewed were three religious leaders in Kampala and two in Mbarara, two legal professionals in Kampala and one in Mbarara, and three NGO/CBA representatives in Kampala and one in Mbarara.

Focus group discussions took place with two groups of people living with HIV/AIDS (one female and one male) in both Kampala and Mbarara. One meeting of a

discussion group, composed of people of both sexes living with HIV/AIDS, was held in Kampala, and two in Mbarara. Focus group discussions with counsellors also took place in Kampala (1) and Mbarara (2), and with community workers in Mbarara (1).

Observations took place in hospital environments where people with HIV/AIDS received care. Attention focused not only on the way in which such individuals were received in reception areas, but also the manner in which staff responded to their needs. Additionally, by means of observation, it was possible to record how relatives and caregivers within the home responded to people with HIV/AIDS.

Sampling was carried out on the basis of awareness of the contexts and settings in which HIV/AIDS-related DSD has been documented to exist.

## **FINDINGS**

---

In this section, we will look at the common kinds of DSD identified by respondents. Next we will discuss the determinants of HIV/AIDS-related DSD, with a particular focus on likely explanations for continuing discrimination in Uganda. Finally, we will examine responses to HIV/AIDS-related DSD. Here the emphasis is on the reactions of people with HIV/AIDS and their caregivers to continuing DSD in Uganda.

Within each of these three sections, the three different settings of inquiry are explored: the individual and family, institutional and community, and policy settings. Each section contains extracts from focus groups and individual interviews drawn – where possible – from both research sites.

### Forms of HIV/AIDS-related DSD

#### Families

Although anti-discrimination measures have been a central feature of Uganda's response to the AIDS epidemic, in each site, approximately equal numbers of people with AIDS reported having been rejected by their families. This finding initially surprised the research team, who had considered that extensive education campaigns, and the fact that nearly every household has been affected by HIV/AIDS, would have had

some effect in reducing HIV/AIDS-related DSD in the community. Yet comments such as the following were not uncommon.

**“On revealing my serostatus to my family members, I was surprised, my mother rejected me. I felt very bad, lonely, and rejected.”** (Man with AIDS, no details)

**“I was isolated. My family deserted me. Even my father, who gave my hand in marriage [to the man who infected me], never bothered to visit me even during the time when my husband was very sick. I was so disappointed and annoyed because it was my father who arranged for this marriage. He no longer cared.”** (Woman with AIDS, Kampala District)

Two main forms of DSD were reported within the family setting: women were neglected by their parents and especially by their parents-in-law, particularly following the death of a son; and wives were neglected by their husbands.

In both sites, the revelation of a woman’s positive serostatus to her husband was reported to lead to neglect.

**“I was lucky. I spent a good couple years with no serious infection. But unfortunately, I started falling sick again, my legs were very painful, I had a skin allergy. People started telling my husband that that’s real “slim.” My husband became frightened and worried that I could be having “slim” (i.e. AIDS). He had me taken to witchdoctors but all failed. So he deserted me and left me in the home with my co-wife. I waited in hope for a week that he was coming back as he left me very ill, he never returned.”** (Woman with AIDS, Kampala District).

Fear of a husband’s reaction may prevent some women from sharing their status. Being blamed, victimized, and deserted were common fears.

**“Married women with HIV do not reveal their positive serostatus to their spouses for fear their husbands would say “You got it first ... you are the one who brought it in the family.” Therefore often when you ask them what they will tell their husbands, or what they are going to do [they say] “I will keep quiet.” “Why?” “He will say I have brought it and he will send me away.”** (Female counsellor, Mbarara District)

Although the study suggests that the burden of DSD within the family falls upon women, there were reports of women abandoning a husband following revelation

of his positive test result. However, men with HIV/AIDS participating in a focus group in Kampala suggested that such cases may be explained by the feared punitive reaction of family members: "Relatives always blame their widowed-in-law for having 'killed' their son in case he dies of AIDS. Other reasons [for running away] are that the widow fears the likely reprisal" (men's focus group, Kampala District).

The different treatment accorded to women in the epidemic was evident throughout the research. One of the most striking forms of this difference emerged in relation to inheritance, particularly in terms of remaining in the marital home if the husband died. One community leader from Kampala District reported his experience of dealing with parents-in-law who wanted the wife to leave:

***“In some other instances, parents of the dead husband come to the home of the deceased and start demanding the property ... even reaching the extent of telling the widow to vacate the house as it had been decided that she should be taken back to the parental village.... For instance, there is a case of a very clever family who said that they could not afford to pay the house rent, so they were taking the widow to the village in order to care for her from there. As LCs [local council leaders] we intervened.... They wanted to take her to the village and thereafter chase her away and take charge of the property left behind.... And in addition, the late husband had left a project behind which could be used to pay the rent. ”*** (Community leader, Kampala District)

Conflict between parents-in-law and daughters-in-law was also reported in Mbarara District.

***“Where there's a married couple and one of them has passed away – actually, if it's the husband who's passed away and left a widow behind ... you might find that the widow is likely to be tossed [out] you know! Here and there! To be sent away, to be deprived of property for the reason that these people, the relatives of the husband, may want to have a share of what's left behind. ”*** (Male counsellor, Mbarara District)

This was precisely the experience described by a woman in a focus group in Mbarara: "One father-in-law sold land that belonged to his deceased son, including the plot where the widowed daughter-in-law lived. She was told to go where she got AIDS from" (female member of a focus group, Mbarara District).

The problem of being denied one's inheritance or succession rights was not necessarily brought about by the death of a husband. Fathers and other relatives appeared unwilling, research respondents told us, to bestow bequests of any kind upon women with HIV and their children, regardless of the latter's serostatus. One woman with AIDS told us that her father had decided to give his estate to a daughter whose where-

abouts he did not even know rather than to her. The reason he gave was that she was “going to die”:

**“In my family, we are two sisters, the second one we are not sure of her whereabouts as of now.... My father when he was distributing his estate he said ... ‘Eeh! Do you count Namuli as a human being? She is going to die!’... I was really annoyed, he said he should give [my share of the estate to] Nalukwago [the sister].”**  
(Woman with AIDS, Kampala District)

The same woman’s parents-in-law reacted in a very similar way. Additionally, children of women who have HIV or AIDS are ostracized: “On the side of my husband, they were allocating his estate, they said ‘Eeh! Why give Namuli’s children ... they are also going to die because they have ‘slim.’... Those children do not have any future.”

Yet, these kinds of experiences were not exclusive to women. In the Kampala District, one man with AIDS described his family’s reaction when he announced he was getting married: “They refused to contribute money, saying ‘Why should they get married? They are going to die and the money will not be well spent. Why don’t we keep it for the purchase of their coffins?’ To them you are like rubbish. They no longer respect you’ (man with AIDS, Kampala District).

Our research suggests that these kinds of experiences lead to a more general climate of secrecy about HIV/AIDS within families. Individual family members do not reveal their serostatus to anyone and therefore are unable to access the familial care that might otherwise be provided. As one man observed, “Well, I wanted to keep it as a secret because I did not want to frighten my parents, sisters, friends, etc.” (man with AIDS, Kampala District).

### Community

Similarly, and perhaps not surprisingly, community-based rejection of people with HIV/AIDS was also reported in both sites. A community leader in the Kampala District described how families interact with other families living with HIV/AIDS in the same community:

**“Through normal association, some families may not like their children to play with that family which has AIDS patients in fear that they might also be infected. But mainly through quarrelling ... through exchanging ‘hot words.’ One may ask, ‘For how long are you still breathing? You are going to die!’”**

The research also revealed that a significant undercurrent of suspicion has arisen in the community in relation to HIV/AIDS. In both sites, the research team was told about gossip and finger-pointing relating to HIV status. In part, this was connected to the prevalence of HIV in the community: AIDS has become a hot topic of discussion and

interest, perhaps because anecdotal evidence suggests that most households have been touched in some way by the epidemic. A woman with AIDS described her experience of finger-pointing, gossip, and isolation thus:

**“Because my husband was sick, the whole world came to see and stare. When we used to pass in the streets, they all came out to see and even made lines to stare. When he died they all knew. One time, my neighbours beat up their kid because he had come to my place.... I was very perturbed. I was so annoyed and asked myself why they had to beat him and stop him from playing.”**  
(Woman with AIDS, Kampala District)

In addition, it was reported that people who were friends with people with HIV had a tendency to keep their distance in case they too were thought to have AIDS. This unfortunate corollary of HIV stigmatization means further isolation of people affected by the epidemic. As persons who relate to those infected are also presumed to be infected and thus stigmatised as well.

The presence of AIDS service-providers is perhaps another vehicle for gossip in the community. Some people felt that, because many of these organizations are well known and have a high profile, associating with them provided a significant hint as to HIV status:

**“One can suspect that a person is HIV positive without them telling you. If he/she goes to TASO [but] has not told you, you get to know the reason why.”** (Female community leader, Kampala District)

**“Most of the men do not want their wives who are PWAs to go to TASO because they do not want other people to know for fear of condemning the family.”** (Focus group member)

Many respondents suspected a salacious motive for the gossip, which related to the sexually transmitted nature of most infections:

**“I think it’s because of the sexual part of it that people tend to talk more. If AIDS was something transmitted like ... cholera, I mean, no one will bother talking about it so much like that. I think being a sexually transmitted disease, it’s as if it’s a shameful disease. That’s why they talk about it.”** (NGO representative, Mbarara District)

With such intense interest about HIV in the community, it is not surprising that many respondents decided to keep their status a closely guarded secret from almost everyone, including friends and relatives. As one woman with AIDS put it, “It’s a secret between me and the patient [her husband]. Ms Ruth [an AIDS counsellor] comes to see us, but I cannot tell the villagers because they keep on pointing fingers.”

Although a rather grim picture of life in the community emerges from the research, there were also reports of improved treatment of people with HIV/AIDS, suggesting that AIDS education and experience of HIV in the community were beginning to make a difference. A community leader told us:

**“In the past, fellow villagers feared to go near that person or saw him/her as filthy, but after this greater AIDS sensitization over the radio, people have learned how AIDS is transmitted, they no longer treat those infected badly”** (Female community leader, Kampala District).

Similarly, reactions to HIV/AIDS NGOs were reported to change once education work had been carried out:

**“We have this vehicle labelled ‘AIDS Information Centre.’ Sometimes when you are driving through, certain people you will hear them shouting, ‘Ooh! Those ‘slim’ people! They are sick.’ But again when you are passing through certain communities which are sensitized about what you do, you will not hear such kinds of talk.”** (Male counsellor, Mbarara District)

A man who acknowledged the existence of continuing “negative attitudes and isolation tendencies” in the community also felt that the situation may be slowly changing: “Maybe the situation is changing, because I think there has been a lot of sensitization, and I think now people are getting to know [about] sharing cups, plates, drinks” (Man with AIDS, Kampala District).

## NGOs

Although the research team heard a number of accounts about inheritance problems between women and their families, financial difficulties also existed outside the family context. Specifically, women with AIDS risk losing the few sources of income to which they have access. For women on low incomes who discover their HIV status only when they become seriously ill, financial support is crucial. Yet one women’s representative of an NGO told us that this is precisely when loans are unlikely to be available:

**“Here in Women’s Finance, we do not discriminate. What we do, we give credit to women low-income earners, but then, not like we’re discriminating against HIV people or not, but when we find this person is going down, deteriorating, we tend not to give them credit.”** (NGO women’s representative, Mbarara District)

Surviving financially following the death of a husband to AIDS-related conditions is often very difficult, whether or not the woman herself is HIV-positive. Indeed,

the plight of some women is such that a negative test result may be seen as a misfortune. A positive result can give them access to services and financial assistance that mean a future with some support and help. A negative test result is likely to mean no access to services, and this may cause particular difficulties for women who had been banking on NGO support following their husband's death:

**“There [are] those who have lost their husbands with full-blown symptoms of AIDS yet they have not tested.... They come here expecting to be positive and of course the reason for making them take a decision is [that there is] an organization supporting orphans of those who are positive, or they hear there are.... OK, for instance, TASO is well known, there are some things they give in TASO to prolong life.... So when you give a result which is non-reactive to such a lady ... she will really want, almost faint.... She was expecting a positive one to go and benefit from that assistance.”** (Female counsellor, Mbarara)

A similar point is made by a male counsellor:

**“When they come, they are thinking that they are victims.... And they come with the hopes that after getting the positive results ... “I will get the help.”... We have actually got problems with some ladies saying “I think you are deceiving me, why? I know my husband died of the ‘thing’, of the virus. Now you’re telling me I am not infected, yet I want to go to TASO.””** (Male counsellor, Mbarara District)

The research would suggest, then, that women with HIV/AIDS, or the female partners of those with AIDS, merit particular attention in the fight against DSD. Property rights as well as entitlement to benefits and to care and services all need to be considered carefully with a view to taking further action to protect women's interests and promote their rights.

### Health care

In contrast to some other investigations (Asingwire, 1992; Malcolm, 1994), this study found an unclear pattern with respect to stigmatization and discrimination within the health care setting. Individual respondents noted that, in the early days, health care workers had tended to pay less attention to people living with HIV/AIDS in the belief that they were going to die anyway. Moreover, there was some evidence of private practitioners charging AIDS patients more than their other clients. However, the current situation was perceived as having normalized to some extent. Cases of HIV/AIDS had become so ubiquitous that special responses seemed unnecessary. That said, some health care workers still did not address HIV and AIDS “squarely” with patients, perhaps because of personal anxiety or a lack of adequate education about the psychosocial needs of people living with HIV/AIDS.

The majority of medical staff interviewed would appear to have adequate knowledge of HIV and a commitment to providing equal treatment to people with AIDS.

*“At one time we were told we should regard every patient as a potential HIV patient. So now when you are dealing with someone and if you are going to be exposed to any fluids or blood, you always put on gloves. . .”* (Medical superintendent, Mbarara District)

*“There should be no (I will use your word) “discrimination” between a patient with AIDS, a patient with tuberculosis, or a patient with whatever, to a medical worker. If you are a properly trained medical worker, you should look at these people as patients. ”* (Doctor, Kampala District)

These remarks notwithstanding, there did appear to be some uncertainty among more-junior staff regarding the need for universal precautions, although the extent of this was unclear.

What was clearer from the research, as is mentioned above, was that association with well-known AIDS NGOs was feared by a significant number of people, especially among classes above the very poor, because of the stigma of that association in the community. Similar problems might be expected to occur within health care units. More research into the area of confidentiality in health care environments would therefore be helpful.

Finally, many TASO clients interviewed by the research team expressed concern about the treatment they received in the general health care system. They expected to get the same good quality treatment in public health facilities that they do in TASO. One client in Mbarara, for example, commented that “They make us sleep on the floors when we are admitted in the hospital.” On further interrogation and observation, however, researchers noted that the hospital was overwhelmed, and patients were lying on the floor regardless of their condition. Care, like treatment, was by necessity allocated in the same non-preferential way. It was difficult, therefore, to substantiate the claims of respondents about discrimination in health care settings.

## Workplace

The research identified a range of issues relating to stigmatization and discrimination in the workplace. It was reported that some companies tested prospective employees prior to offering them appointments; others (including prominent multinational companies working in the country) were said to require workers to take an HIV antibody test before sending them on what were considered to be expensive training courses. Still other companies were said to test workers opportunistically, assigning lighter jobs to those who tested positive. A few companies reportedly paired people with HIV/AIDS with “deputies” who could take over when the affected person became ill.

Except in a few instances, respondents felt it difficult to be open about their serostatus at work. This reticence was as much a product of self-stigmatization and concern about the possible responses of workmates as it was linked to the likely actions of employers. A traditional healer recounted the following story:

***“I remember a young woman I was treating. She didn’t have any symptoms when she went to Nairobi but when she came back she had a bad rash. The staff she was working with then went to Personnel and said ‘Why do you have a woman like that in public?’ I went and talked to the company and asked them not to demote her. Please don’t demote her, please don’t move her. But after six months, she died. She heard all the rumours and just gave up.”***

Another woman explained, “It is not good to reveal one’s serostatus because once your friends [at work] know, they start spreading rumours which may even reach schools where one’s children study, and obviously such children get affected.”

Overall, it seems clear that, despite government efforts to encourage openness and discourage discrimination, serious anxieties prevent people from being open about their serostatus at work. As one man put it, “Even when the boss would not have terminated your services, the rumours from the colleagues are enough to force him to take action, and give your job to somebody who is not ‘sick.’” A woman with AIDS told us, “In the past I used to give AIDS awareness talks in big statutory bodies. They used to tell me that AIDS is not *their* problem” (woman with AIDS, Kampala District). Clearly, further study is required of the overt and more covert forms of HIV/AIDS-related DSD in the workplace.

### Religious institutions

It was clear from interviews undertaken with religious leaders that churches have a somewhat contradictory attitude towards people with HIV. While stating that “Jesus did not come for the righteous but for sinners,” many Christian leaders clearly regard people with HIV as “promiscuous” wrong-doers. One church leader told us that “AIDS is an epidemic that has come to the world because of promiscuity and this has resulted in AIDS and other STDs.” Muslim leaders, too, came in for some criticism: “Religious leaders, for me, I think they take someone with the virus as an adulterer. Because I heard one time an imam saying, ‘That Mister so-and-so has been having a lot of sexual partners.’ That is what they were saying!” As a result of attitudes such as these, many respondents with HIV, not surprisingly, felt that they could no longer attend religious services. It was also felt that the kinds of attitudes held by church leaders fostered a false sense of security among some married people and others who did not consider themselves “promiscuous.”

In contrast, it was noted that women, especially widows, used places of worship as a refuge and found comfort in the seemingly accepting or tolerant associations

and interactions. One HIV-positive woman from Mbarara said, “I feel fulfilled when I go to church. That is when I feel as good as anybody else.”

### Community-based associations (CBAs)

A sizeable number of respondents told us that, since they had tested positive, they had withdrawn from community-based associations.<sup>3</sup> Some stopped going because they perceived that people within those associations were making judgements behind their backs. One focus group member said, “Although you could not visibly see them, whenever I went to attend CBA meetings, people would point fingers at me saying my husband died of AIDS and that I am a moving corpse. I had to stop going to their meetings.” Others said that they could not afford to pay the CBA subscription fees, or preferred saving the money for an emergency. Another reason given for withdrawal was that people feared that their status would be revealed to the whole CBA if they continued attending.

While some respondents no longer attended CBA meetings, it is unclear to what extent discrimination in the context of CBAs is perceived or actually experienced. More research in this context is clearly necessary (see “Conclusions”).

### Self-stigmatization

Beyond the enacted (experienced) stigmatization and discrimination documented above, was the perceived stigma that led individuals to police their own behaviour to prevent their serostatus from becoming known to others. This appeared to be the commonest and most difficult form of stigmatization to address. In some cases, self-stigmatization resulted in an individual’s avoidance of particular settings. For example, despite widespread awareness campaigns in Uganda, and the fact that the response has been very encouraging, only a very small number of middle- or upper-class citizens have access to HIV/AIDS services. As documented above, some people living with AIDS avoid community-based associations, or even the workplace, due to perceived stigmatization. In relation to the employment context, counsellors in a focus group in Kampala emphasized how they had “encountered clients who have not been dismissed from their work but who have sort of dismissed themselves due to self-stigma.”

Others saw self-stigmatization as triggering an uncooperative attitude among individuals who refused to accept the help and support offered to them. “Some people are not very supportive because the PWA him/herself may not be cooperative to other members [of the family]. He/she may stigmatize him/herself, hence rejecting the help from other people” (Focus group discussion, Mbarara).

---

<sup>3</sup> These include institutions like the Mother’s Unions, Rotary Clubs, and credit groups.

## Determinants of HIV/AIDS-related DSD

Identifying different forms of HIV/AIDS-related DSD is a first step to identifying their determinants. Tackling the determinants of DSD would provide a significant boost to tackling DSD itself.

### HIV/AIDS information

Early on in the research, it became clear that, although the Ugandan population had received education on HIV/AIDS issues (Nuwagaba, 1994), significant gaps in understanding remain, some of which are likely determinants of DSD. Our research findings would suggest that, while many Ugandans are aware of the “facts” about HIV/AIDS (recognizing HIV transmission routes, for example), this does not always affect everyday action. This gap between what, at one level, people *know* and what, at another level, they may *do* makes it possible for HIV/AIDS-related DSD to continue. Examples of this were given in family, community, workplace, and health care settings:

**“Some people think that contact with PWAs or being close to them can lead to infection. Others think that to get AIDS, one must have been promiscuous, while to others it is a curse on the family.”**  
(Focus group member, Mbarara District)

**“Of course in the taxi that carries 12 people, if a person infected sits on a seat, many people may want to pass the seat, an indication that they would not like to sit near a person who is infected by HIV or fear to be infected by the disease the person is suffering from. Things of such nature we see them in the community. It’s somehow lack of enough information about HIV, or the fact that they do not take the issue of HIV very serious.”** (Male counselor, Mabarara District)

While some people shy away from anything they consider to be unusual or risky there was evidence of a greater acceptance of people with AIDS; nonetheless, instances of stigmatization and discrimination were still reported. For example, some people with AIDS reported that, because of the fear that HIV was easily contagious, their families refused to share certain household utensils with them. Others said that they were moved out of the family home for the same reasons. Examples of such attitudes and beliefs were identified in both sites.

### Lay/culturally determined beliefs

Even when people have good information about transmission routes, other factors can interfere with this basic understanding. Among some trained medical staff, for

example, fear of contracting HIV appeared to be a significant factor affecting practice and attitudes. As noted above, there was some uncertainty about the need for universal precautions. One case cited by a man with AIDS concerned a doctor who worked in specialist immune suppression clinics and who appeared unable to provide appropriate care for people with HIV/AIDS:

***“If he was attending to a person who had the virus, after reading from the notes of the patient indicating that he is HIV positive, you could detect his uneasiness as a person. Time came when he requested me to take the blood samples on his behalf for fear of touching that blood! I was forced to ask him one time why he felt uneasy when attending to PWAs. He replied that he really doesn’t know, but when he saw a PWA he felt bad. And in fact he finally requested a transfer. It made matters worse when he learnt that I am also a PWA because we used to sit in the same office.”***  
(Man with AIDS, Kampala District)

Other factors “interfering” with knowledge about HIV transmission were beliefs that contracting HIV is related to “sinful” behaviour – a message unfortunately reinforced by some religious leaders in Uganda – and that to be married or religious therefore provides a high degree of protection. A Catholic woman living with AIDS told us:

***“When I learnt that I had the disease, I was deeply hurt and despaired. I lost my temper and told my counsellor, “You must be joking! I am a married and saved woman, how can I be having ‘slim’? ‘Slim’ the disease affects those who are not married, people who are single.”***” (Woman with AIDS, Kampala District)

Traditional cultural beliefs within communities about the existence of witchcraft and curses also affect how people understand messages about HIV transmission and respond to someone who has AIDS. As one community leader in Kampala District noted, “At first people thought that the disease was a result of witchcraft after that person had done something.” A woman who had had HIV for ten years was told by her sister-in-law that she should take another test and that her husband had died as a result of witchcraft rather than AIDS-related conditions. Her sister-in-law’s assertion was grounded on the belief that it was not possible to live for ten years with HIV, and that death was imminent following a diagnosis.

Another woman told us that she was the first to be known as HIV-positive within her family but that, since then, several other family members had become sick and died. “It looked like I had put a curse on my family and they hated me for that” (Woman with AIDS, Kampala District). A man with AIDS recounted a similar story: “In my family I was the first to get AIDS. At one time during funeral rites, an announcement was made that I had got AIDS and had brought a curse to the family” (Man with AIDS, Mbarara District).

Local sexual beliefs are also determinants of HIV/AIDS-related DSD. Long-held ideologies make it seem logical that while men may seek many partners (and receive social status for doing so), women should limit themselves to only one. To some extent, such practices are legitimized by the traditional marriage bond, which denies women the opportunity to object when their husbands put them at risk.

### Sexual shame

Ignorance, fear, and lay beliefs are not the only determinants of HIV/AIDS-related DSD. In Uganda, HIV is generally regarded as a sexually transmitted disease. The research team was told on several occasions about erroneous assumptions being made about the mode of transmission in the case of particular individuals. In one focus group discussion, for example, the following story was told about one young man's funeral. The young man's father lamented, "Do you see the result of someone who conducted himself the way he did?" Yet no one was sure that the young man's death was related to HIV at all. The impact of HIV upon young Ugandans has been such that some people almost inevitably make a connection between youth, sex, and AIDS. The sense of sexual shame that often accompanies AIDS in the community acts as a barrier to accessing care and prevention services.

### Finance

Financial issues can fuel DSD within the family setting, especially when resources are in short supply. Focus groups suggested that families' acceptance of people with HIV was in part conditional upon the availability of resources. One group member told us that "PWAs live freely in families in which they belong and experience love and care. But this is only as long as the family has enough resources. If the resources start dwindling, then the PWA take the blame because after all he is going to die within a short time." Another said, "We are useless to people because they know we are going to die. People wished a PWA would die soon so as not to waste the already scarce family resources." Such views tie in closely to ignorance relating to HIV. Many families appear to believe that HIV and AIDS are the same and that people with HIV die very soon after being diagnosed.

It was reported that, although such feelings were not always expressed verbally, they had still been made apparent to the family member with HIV. There was a sense that the person with HIV was to blame for reducing familial savings. In contrast, those who were financially independent tended to receive significantly better care, and with a much less grudging attitude from family members: "A person who is well-off and is independent is neither isolated nor discriminated against like the poor and dependent ones" (focus group member).

A man with AIDS suggested that reasons for caring for PLWA who have money may have much to do with financial gain:

**“A person who is well off is not easily discriminated against that much, because the carer expects something in return if he cares for you.... When you are well-off, carers are always at hand.... If he is benefiting from you, then you are worth living, useful. They find it very easy tell off they rush to assist you ”** (Man with AIDS, Kampala District!)

It should be noted, however, that because HIV-related illness can be protracted, resources may be severely reduced. The burden of caring, coupled with dwindling resources, can make some caregivers’ lives extremely difficult. In most cases, caregivers are spouses who also have to cope with the fear of going through the same experience.

### Lack of effective policy

Although the Ugandan Government has promoted excellent principles of non-discrimination in its National Strategic Framework on HIV/AIDS (cited in “Background” above), such guidelines carry very little legal weight. This is a matter of serious concern. Legal representatives told us that Uganda has no specific laws regulating HIV/AIDS and its consequences, including the rights and responsibilities of people with AIDS. The same was reported to be true in the case of inheritance, custody of children, and general ostracism, which all, as documented above, particularly affect widows. Clearly, government action is needed to translate recommendations into legislation that can make a difference for people living with HIV.

### Responses to HIV/AIDS-related DSD

**R**eported responses to discrimination, stigmatization, and denial in terms of HIV/AIDS were of three main types. First, there were responses of an individual nature. These included revealing one’s HIV/AIDS status to family and community members. Importantly, disclosing one’s status in this way was found in some cases to diminish the stigma associated with the condition. As reported in a counsellors’ focus group in Mbarara,

**“One lady who had AIDS had earlier been rejected by the relatives and the community. But after she went public and declared her serostatus, those who had deserted her now come for assistance and guidance on how to cope with AIDS. ”** (This same woman subsequently became part of the AIDS Education drama group in TASO.)

Another described the following experience: “Declaring one’s status gives you a sense of self-worth. It removes a spirit of isolation and self-condemnation and increases love and care from other people” (Person with AIDS, no details).

In these two cases we can see how acknowledging one's serostatus may lessen both the felt and enacted components of HIV/AIDS-related stigma. Many other similar examples were given by research respondents. For some women, an additional perceived benefit of sharing their serostatus was that it lessened the likelihood that men would approach them for unwanted sexual relationships.

Nevertheless, it was clear from interviews and focus group discussions that respondents from rural communities were less likely to reveal their seropositivity than those from urban ones. In rural areas, openness may be constrained by gossip, by inadequate HIV/AIDS prevention and care, and by the absence of adequate support systems for people with HIV/AIDS. More intensive educational work and other activities may be needed in rural communities.

Some respondents did not have the strength to be fully open about their condition. For them, a more secluded and often isolated life was seen as the only option. They avoided situations where DSD might occur. According to a male counsellor in Mbarara District, "Somehow psychologically, they still feel that they will not be accepted by members of the public. That they will be looked at as people whose behaviours have deviated from the others in society."

The power of counselling to support people in confronting HIV/AIDS-related DSD and in being more open about their serostatus was a recurrent theme throughout our study. In a focus group in Mbarara, one person told us, "Once you have been counselled, you don't mind about people's comments and reactions against you." However, other responses to DSD suggest that counselling needs to be consistent and ongoing if it is to have a tangible impact on the lives of people with HIV. One counsellor in Mbarara told us how his clients responded to HIV/AIDS-related DSD:

***“Actually, most of them at the beginning feel like dying, feel like committing suicide, because, you know, being tossed around. Everybody doesn't want to handle you, everybody doesn't want to help. They have suicidal, I think, suicidal tendencies. They feel like, “I wish I could die!””*** (Male counsellor, Mbarara District)

At the family and community levels, respondents reported that HIV/AIDS-related DSD had lessened as more families became affected, and as support was more forthcoming. In a focus group in Kampala, one man said, "Many people (families) have lost their dear ones. It is due to this reason that they come to help with the situation and not to stigmatize and discriminate against people with AIDS." In a similar group discussion in Mbarara, a man reported: "My family and relatives from the time I revealed my serostatus have been supportive, sympathetic, and caring. I was delighted that my family accepted me. They advised me to go to TASO for long life, care, and support. One of them organized a TASO counsellor for me." Although this sounds positive, it should be remembered that the responses women received were likely to be very different from those accorded to men.

Many health staff have been reported as taking active steps in their own institutions to challenge HIV/AIDS-related DSD. In Mbarara, some health workers were even

planning to have money deducted from their salaries every month to demonstrate their support for people with HIV/AIDS. As the administrator of the local hospital explained, “Health workers in this area have a socio-medical committee specifically aimed at addressing the social aspects of persons living with AIDS. They are proposing to fund it by deducting some money from their monthly salaries.”

A key informant in Kampala pointed out that “The attitude of health workers towards people with AIDS and HIV is positive [now] because almost everybody has been affected. Nearly everyone has lost a relative, a friend, or a neighbour.” Equally, the fact that those who give care have not become HIV positive has encouraged others to become caregivers within the community. This suggests that, to challenge DSD, it is important not only to provide information but also to “model” best practice to some degree.

As mentioned earlier, efforts have been made at the governmental level to enact legislation to protect people with HIV/AIDS from discrimination and to promote a more compassionate and caring response. While an evaluation of the impact and effectiveness of this legislation was beyond the scope of this study, the existence of a clear legislative framework to promote the human and civil rights of people living with HIV/AIDS is a crucial component of any programme to lessen HIV/AIDS-related DSD.

## CONCLUSIONS

---

This study has recorded unsuspected but declining levels of HIV/AIDS-related discrimination, stigmatization, and denial, particularly in relation to familial and community attitudes towards people with HIV. HIV/AIDS-related DSD were also found in health care and workplace environments, although in both of these settings there was evidence of some kind of “normalization” of response whereby at least some people with HIV/AIDS were being responded to more positively. Despite progress in these areas, the importance of self-stigmatization was highlighted repeatedly throughout the study.

AIDS-related DSD was particularly apparent in relation to the inheritance and succession rights of women: suspicion about HIV and AIDS tended to cause the husband's parents to react negatively towards the daughter-in-law and her children. The belief that an infected individual might die in a short period of time, along with continuing fears of witchcraft, further compounded the difficulties many women faced.

DSD was reported within community-based associations as well as among influential religious leaders. Respondents reported that the latter gave mixed messages about routes of transmission and appropriate attitudes towards those with HIV. We have also heard numerous stories about assumptions that have been made by community members about people who associate with AIDS-related NGOs.

*Determinants of HIV/AIDS-related DSD* identified in the study echo those found in previous research: <sup>(i)</sup> Knowledge levels may have been recorded as good, but people with HIV in community and family settings continue to experience DSD. Knowledge about the life expectancy of a person with HIV was found to be particularly poor. <sup>(ii)</sup> Lay and culturally determined beliefs some of which, as recurring examples indicated, are based on witchcraft would also appear to have a significant effect on people's ability to take in information messages about HIV and to change their behaviour and attitudes accordingly. <sup>(iii)</sup> Within families, concern about the financial burden of caring for someone with HIV would also appear to fuel HIV/AIDS-related DSD. <sup>(iv)</sup> Other problems relating to the predominantly sexual nature of HIV transmission: many Ugandans seem to feel that HIV is a badge of sexual shame, and this attitude also affects the care that people with HIV are likely to receive.

While there is evidence that information campaigns have improved the situation as regards DSD in the community, there is still much work to be done in challenging AIDS-related stigmatization, and especially self-stigmatization. This is particularly the case in terms of a legislative framework. Although the Ugandan government has excellent guidelines in place, these have not yet been translated into enforceable laws to protect people with HIV/AIDS from the kinds of DSD documented in this report.

*The outcomes of HIV/AIDS-related DSD* identified in this study suggest that counselling services are effective in dealing with people's feelings of isolation, embarrassment, and despair following a diagnosis of HIV or AIDS. The research also suggests that DSD has serious consequences for people living with HIV/AIDS, although it was suggested that being open about one's serostatus boosted feelings of self-worth and confidence.

This report reveals significant levels of DSD; yet there are some positive features that must be stressed. First, the Ugandan Government has been and continues to be supportive of a general climate of anti-discrimination in the country. Second, information campaigns have improved people's knowledge levels. Third, the health care system would appear to be relatively enlightened in its dealings with and attitudes towards people with HIV, at least in contrast to cases reported in other studies. Finally, it seems that services provided by AIDS NGOs and other groups can help people with HIV become more assertive, be more open about their serostatus, and live truly "positive" lives.

## Recommendations

It would be inappropriate to conclude this report without making reference to the question "What next?" What follows is a list of key recommendations that have emerged from our findings. We hope that these can be taken forward by key organizations and institutions in order that Uganda can improve its proud record of resisting HIV/AIDS-related DSD.

- Efforts to tackle HIV/AIDS-related DSD have been assisted by governmental guidelines issued as part of the National AIDS Policy. There is need to enact sectoral legislation that cover the full range of rights issues identified in this report.
- Existing laws and new legislation must address issues of inheritance, health care, employment, education, housing, and social security.
- Although education and information campaigns have been mounted with some success by both government and NGOs, it is vital that specific attitudinal work be undertaken to challenge particular stereotypes and myths about HIV. In particular, the idea that only promiscuous men and women can get AIDS must be challenged by individuals and institutions throughout the country.
- There is evidence that counselling and other support work by NGOs and other organizations is valuable in countering DSD. Such services should be developed and expanded.

- People with AIDS should be encouraged and helped to be more open about their serostatus and to fulfil their responsibilities to the wider society, thereby lessening DSD.
- Greater attention needs to be paid to the gendered nature of DSD in Uganda. Women's rights of inheritance, social security, and housing should be protected, and women's specific health needs should be addressed.

### Future Research

This report has highlighted a number of areas in which more research would be beneficial. These include:

- the health care sector
- the employment sector
- community-based associations
- the legal framework.

We would also welcome further research, whether in Uganda or other countries, into the forms, determinants, and outcomes of HIV/AIDS-related DSD. More research on cultural factors that may impede progress towards a society fully educated about AIDS would also be beneficial.

Although scholarly research often calculates the cost of HIV treatment, or the cost of lost work-hours through HIV-related illness or death, the cost of HIV/AIDS-related DSD is rarely commented upon or estimated.

Large-scale studies are needed to look at the social as well as the economic impact of DSD on families, communities, the health care system, the labour force, and productivity. Such studies may lay the foundation for the development of educational and other activities to tackle DSD more effectively.

Above all, it must be recognized that there can be no effective response to the HIV/AIDS epidemic – especially in relation to access to care and social support – unless DSD is positively and constructively addressed.

## REFERENCES

---

- Ankrah, EM, et al. (1993) AIDS and the urban family: its impact in Kampala, Uganda. *AIDS Care*, 5, 1:55–70.
- Asiimwe-Okiror, G, Opio, AO, Musinguizi, J, Madraa, E, Tembo, G, and Carael, M (1997) Change in sexual behaviour and decline in HIV infection among young pregnant women in Uganda. *AIDS*, 1757–1763.
- Asingwire, N (1992) *Towards the development of AIDS policy in Uganda*. [MA dissertation]. Hamilton, ON, Canada, McMaster University.
- Babikwa, D, and Kirumira, E (1993) *Factsheet on socio-economic indicators and implications of the AIDS epidemic*. Child Health and Development Centre.
- Baite-Kitonsa, S (n.d.) *Law, ethics, human rights and AIDS training manual for community awareness*. Network on Law, Ethics and HIV/AIDS, Uganda.
- Barnett, T, and Blaikie, P (1992) *AIDS in Africa: its present and future impact*. London, Belhaven.
- De Bryn, M (1992) “We are all people living with AIDS”: myths and realities of AIDS in Brazil. *International Journal of Health Services*, 21, 3:539–551.
- Macro International (1996) *Uganda demographic and health services 1995*. Calverton, MD, USA.
- McGrath, JW (1992) The biological impact of social responses to the AIDS epidemic. *Medical Anthropology*, 15:63–79.
- Malcolm, A (1994) *HIV and AIDS related discrimination, stigmatization and denial – forms and contexts: a discussion paper*. Geneva. World Health Organization.
- Nuwagaba, A (1994) *Report of the baseline survey for AIDS information, awareness and training programme in southwestern Uganda*. Kampala, Makerere University.
- Rwabukwali, C (1992) *HIV transmission among adolescents in Uganda*. Kampala, Makerere University, Sociology Department.
- Uganda Ministry of Health (1995) *Knowledge, attitude, behaviour and practice study*. Kampala, Ministry of Health AIDS Control Programme.
- Uganda Ministry of Health (1998) *HIV/AIDS surveillance report, March*. Kampala, Ministry of Health.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.

Discrimination, stigmatization and denial have been recognized as important issues to be addressed in the context of HIV/AIDS. Discrimination against those living with HIV/AIDS, or presumed to be infected, is a violation of human rights. All individuals deserve equal respect and dignity, whatever their situation and whatever their health status.

This *Key Material* describes the findings from a study of the nature, determinants and effects of HIV/AIDS-related discrimination, stigmatization and denial in Uganda. The findings demonstrate the profound consequences of these negative processes for the individuals, families and communities involved. Programmatic and policy issues are also highlighted.



Joint United Nations Programme on HIV/AIDS (UNAIDS)  
20 avenue Appia, 1211 Geneva 27, Switzerland  
Tel. (+41 22) 791 46 51 – Fax (+41 22) 791 41 87  
e-mail: [unaids@unaids.org](mailto:unaids@unaids.org) – Internet: <http://www.unaids.org>