



**UNRAVELLING THE DYNAMICS OF
HIV/AIDS-RELATED STIGMA AND
DISCRIMINATION: THE ROLE OF
COMMUNITY-BASED RESEARCH**

CASE STUDIES OF NORTHERN
UGANDA AND BURUNDI

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RESEARCH REPORT SERIES **1**



ACORD

Responding to HIV and AIDS:

Working with Communities

With over 28 million people estimated to be living with HIV in Sub-Saharan Africa alone, the impact of HIV and AIDS on communities has been devastating. Over the last decade, ACORD, an Africa agenda-led organization working in 18 countries in the region, has supported the efforts of people living in poor and marginalised communities to understand the roots of the problem and to find ways of preventing the further spread of the virus and mitigating its impact. ACORD recognizes that the men, women and children living the day-to-day reality of HIV and AIDS have a lot to teach us and seeks to contribute to the global response to the HIV crisis by ensuring that their voices are heard and listened to by decision-makers at all levels.

HIV/AIDS IN ACORD

ACORD views HIV/AIDS as an issue that affects all aspects of its development work, which is aimed at promoting the rights of the poorest and most marginalised sectors of society within Sub-Saharan Africa. ACORD aims to prevent the further spread and mitigate the impact of HIV/AIDS through community-led research and advocacy and working in alliance and partnership with others.

HASAP – ACORD's HIV and AIDS Support and Advocacy Programme – which was launched in 2002, exists to support ACORD's HIV/AIDS work in its programmes. In addition to training and technical support, it facilitates information-sharing and exchanges, both internally and externally, and provides strategic direction and coordination of ACORD's HIV/AIDS-related research and advocacy work.

This publication is a HASAP initiative and is aimed at documenting and disseminating the lessons from research carried out by ACORD in Northern Uganda and Burundi. We hope that others, both within and outside ACORD, will benefit from the sharing of these experiences.



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Written by Angela Hadjipateras

Researched and analysed in Northern Uganda: by Sunday Abwola, Harriet Akullu, Florence Okio and Simon Taban (ACORD Northern Uganda); and in Burundi: by Marie-Josée Kandanga (ACORD Burundi) and Anicet Havyarimana.



Foreword

HIV has been on the global scene for almost three decades now and has reached pandemic proportions, especially in Sub-Saharan Africa, home to over 70% of the global population currently estimated to be living with the virus. The devastation and suffering caused by HIV/AIDS to individuals, families, communities and entire nations are beyond words.

A wide range of actors have come together to take up the challenge of confronting the HIV/AIDS crisis head on. However, the biggest challenge that remains to be overcome is that of HIV/AIDS-related stigma and discrimination. Despite concerted efforts to demystify and enhance awareness and understanding, many people still associate HIV/AIDS with moral decadence and promiscuity, ultimately passing moral judgement on those infected. As a result, people living with the virus (PLHAs) face resentment, isolation, ridicule and are often denied access to their rights and basic services. Such attitudes and behaviours do not only infringe on the rights of PLHAs to respect and dignity, they also act as a strong disincentive for them to make use of any existing services for fear of being 'branded'.

ACORD, an Africa-led international NGO striving for social justice for poor and marginalized people in Africa, has for the last 15 years been at the forefront in mainstreaming HIV/AIDS in its development programmes in Africa. Challenging HIV/AIDS-related stigma and discrimination has been identified as one of the main strategic priorities to be addressed as a key strategy for enhancing the effectiveness of ACORD's HIV/AIDS interventions. To this end, HASAP, the HIV and AIDS Support and Advocacy Programme, helped to facilitate and document the research on stigma and discrimination undertaken by ACORD Programmes in Northern Uganda and Burundi, primarily for the purposes of learning and lesson-sharing. The findings of this research are expected to contribute to learning and debate on stigma and discrimination and to the identification of appropriate strategies and policies for addressing it.

There is no longer any dispute over the fact that challenging stigma and discrimination constitutes a critical part of the equation in the fight against HIV/AIDS. This is even more true in the light of recent developments that have helped to reduce the price of drugs, thereby enhancing the potential for ARVs to be reached by some of the poorest and most needy people living in Sub-Saharan Africa. However, unless stigma and discrimination are challenged, they are unlikely to access these life-prolonging drugs. We hope that this research will inspire all actors, at all levels, to join hands in fighting stigma and discrimination so as to ensure that PLHAs and their families and carers are able to live a long and dignified life in the full enjoyment of their rights.

Dennis Nduhura
HASAP Programme Manager

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In Burundi, Anicet Havyarimana, Legal Representative of APRODEC, ASBL (Association for the Promotion of Community Development) designed, conducted and supervised the research. The management and coordination of the research dissemination and documentation was carried out by Marie-Josée Kandanga, Research Officer for ACORD Burundi.

The research was compiled and analysed by Angela Hadjipateras, Research and Advocacy Officer for HASAP.

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Lastly, we would also like to thank NOVIB, Oxfam International and Cordaid who helped to fund the publication of this research.

List of Acronyms

ACORD	Agency for Cooperation and Research in Development
AIDS	Acquired Immunodeficiency Syndrome
APRODEC	Association for the Promotion of Community Development (Burundi)
ARV	Anti-retroviral treatment
CNLS	National AIDS Control Council (Conseil de la Lutte contre le SIDA)
DFID	Department for International Development
EU	European Union
HASAP	HIV and AIDS Support and Advocacy Programme
HIV	Human Immunodeficiency Virus
IDP	Internally Displaced People
IFAD	International Fund for Agricultural Development
NGO	Non-Governmental Organisation
NOVIB	Netherlands Organisation for International Development Corporation
NUP	(ACORD) Northern Uganda Programme
PLHA	Person Living with HIV/AIDS
PMTCT	Prevention of Mother To Child Transmission
SIPAA	International Partnership against AIDS in Africa
STD	Sexually Transmitted Disease
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
VCT	Voluntary Counseling and Testing
WHO	World Health Organisation



Executive summary

“After two decades...the global AIDS epidemic shows no signs of abating...Among the main reasons...is the persistence of stigma and discrimination against those infected. This outrageous violation of basic human rights drives the disease underground, crippling efforts for prevention and care.”¹

As recognized by UNAIDS and others, ACORD’s own experience over many years of working closely with communities in sub-Saharan Africa to support their efforts to address the far-reaching consequences of HIV/AIDS, has shown that, unless the stigma that still surrounds the disease is tackled, such efforts are doomed to failure. It is this awareness that provided the main impetus for the two country case studies that form the subject of this publication.

Study aims

In line with ACORD’s mission based on the fundamental belief that communities should be the leading actors in the struggle for social justice and equity, the basic premise underlying these initiatives is the view that responses and strategies for tackling stigma and discrimination must be built on communities’ own understanding of the problems and be guided by the solutions they propose. Thus, in addition to identifying the manifestations and consequences of HIV/AIDS-related stigma and discrimination on individuals, families and communities in countries hard hit by the epidemic, an equally, if not more important aim of the research was to engage communities in a process of critical analysis and reflection leading to community-driven action and advocacy for change.

The two country case studies were carried out in Northern Uganda and Burundi as part of ACORD’s work aimed more broadly at promoting sustainable peace and development through supporting peace-building and conflict resolution initiatives, as well as working to alleviate poverty and improve the livelihoods of the most vulnerable groups in society. Responding to HIV/AIDS is a fundamental part of the work of ACORD in both countries. Thus, this research was aimed at strengthening ACORD’s work as well as supporting national efforts to address the effects of the HIV/AIDS epidemic.

Study findings

The findings of the research undertaken in both countries bore many similarities. Stigmatising attitudes and discriminatory behaviour were found to pervade all spheres of life from the home, the family, the workplace, the school, health settings and in the community at large. Because HIV is associated with ‘immoral behaviour’ and sexual promiscuity, people with HIV are often blamed for their condition and denied the sympathy and support given to people with other life threatening diseases. Women and girls are disproportionately affected by these forms of victimization which are compounded by gender-based discrimination. People with HIV also experience neglect and lack of care, even within their own homes. They are also frequently excluded from community gatherings and feasts. The children of people living with HIV/AIDS are subjected to cruel teasing at school and excluded from games and social interaction with their peers. These stigmatizing attitudes tend to be internalized by people living with HIV and can have serious adverse consequences on their emotional, as well as physical health. Stigma also deters people from being tested or even using condoms for fear of being ‘branded’ as HIV positive.



Besides being socially excluded and marginalized, both studies revealed that many people living with HIV are systematically denied their basic human rights, such as the right to health, housing, education and employment protection. For example, there were cases of people being turned away from hospitals or health centers and denied treatment on the grounds that it is not worth “wasting scarce beds and medication” on people “condemned to die”. There were also cases reported of employees summarily dismissed or denied access to training and employment opportunities once their HIV status has been discovered. AIDS widows are particularly vulnerable to violations of their inheritance and property rights. Orphans are also frequently denied their right to schooling and their inheritance is sometimes unlawfully appropriated by their adoptive parents.

The research identified the following key factors that contribute to the incidence and perpetuation of stigma and discrimination: ignorance and fear; cultural norms and values; some religious teachings; the absence of legal sanctions; lack of rights awareness; the design of government and NGO programmes; and inaccurate and/or irresponsible media coverage.

Community responses

In both countries, the research process triggered strong responses at the level of communities where the research was carried out, but also within local leadership structures and other groups and organizations involved in responding to HIV/AIDS at the local and national level. In the first place, the research has helped to raise awareness of the problem and has strengthened broad-based commitment to finding ways of addressing it. That in itself, is a critical first step. In terms of strategies identified, the need for increased awareness and access to information was stressed, as also the need for legislation and enforcement mechanisms to promote and defend the rights of people living with HIV/AIDS (PLHAs). The research also highlighted the need to rethink the design and delivery of programmes aimed at supporting PLHAs and their families and carers. Assistance targeted at these groups was found to give rise to resentment, thereby often aggravating the problem of stigma and discrimination and undermining efforts to support them. Thus, awareness-raising and capacity-building should also be directed at policy-makers and programme managers in order to enhance the effectiveness and take-up of both prevention and care services provided. Finally, the importance of challenging gender bias and discrimination that compounds the effects of stigma experienced by women and girls was also stressed.

Key lessons

- **The importance of involving communities in the analysis of the problem and development of responses:** Community involvement not only ensures that community perspectives and experiences are reflected in the analysis of the problems, but also enhances the sense of ownership of and hence, commitment to seeing through the responses developed. The use of gender-sensitive participatory methodologies to ensure all groups within communities are represented, in particular, those directly affected – PLHAs and their carers and family members - is a critical precondition.
- **The use of research as a tool of awareness-raising:** the research process itself helps to heighten

awareness of stigma and discrimination, which is the starting point for attitude and behaviour change.

- **The role of research in mobilizing action:** Following on from the research, a number of concrete initiatives have been developed to address the problems. In Uganda, steps were taken to establish a bye-law banning discrimination and in Burundi, a network has been established bringing together local and national NGOs and representatives of PLHA Associations to promote and defend the rights of those infected and affected. These initiatives will in turn help to generate increased awareness thereby creating a self-perpetuating cycle of reflection → awareness → action.

Conclusion

As highlighted by these case studies, a comprehensive response is required to address the complex causes and multi-dimensional consequences of stigma and discrimination. Laws to protect the rights of people living with HIV/AIDS are required, but these must be backed up by other measures, such as the provision of accurate, unbiased information to dispel the many myths and stereotypes linked to HIV and AIDS; the greater involvement of people living with the virus in the development and implementation of responses at all levels; support for associations of people living with HIV/AIDS to promote solidarity and mutual help; training for community-based counselors to provide advice and home-based care to patients and their families; increased access to treatment, testing and other services; HIV awareness-raising for teachers, health workers and other service providers, as well as the media, the church and local government officials; and increased collaboration and networking among community-based organizations, national and international agencies to develop complementary and integrated strategies for combating HIV/AIDS-related stigma and discrimination.



Conquering AIDS Tableau at 'Drama for Change' Workshop with local youth groups and artists from Burundi, April 2004



Introduction

“Stigma and discrimination both stymie efforts to control the global epidemic and create an ideal climate for further growth. Together, they constitute one of the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating the epidemic’s impact” (AIDS Epidemic Update, UNAIDS, December, 2003)

The critical importance of addressing HIV/AIDS-related stigma and discrimination in order to curb the further spread and mitigate the devastating impact of the epidemic is now widely recognized by governments, international development organizations and all those involved in the development of strategies to address HIV/AIDS in the world today. The failure to make any significant impact on the spread of the epidemic despite growing attention and increasing resources devoted to the global HIV/AIDS response is one of the main factors that has provoked a re-examination of current responses and highlighted the effects of widespread stigma and discrimination as key barriers to be overcome.

Under the Declaration of Commitment on HIV/AIDS, drawn up at the Special Session on HIV/AIDS of the United Nations General Assembly in June 2001, all Member States undertook to *“develop strategies to combat stigma and social exclusion connected with the epidemic.”* (para 58). However, in reviewing their progress, one in four countries reported that stigma and discrimination remain one of the main challenges they face in the implementation of the commitments made under the Declaration². Thus, there is clearly a need for more work to be done in understanding the origins and nature of stigma and discrimination and the factors that contribute to their prevalence and perpetuation in many societies in order to develop effective strategies for addressing them. It is hoped that this publication, which describes research undertaken by ACORD in Northern Uganda and Burundi will contribute to wider understanding of the problem and provide some useful lessons for actors involved in developing strategies for tackling it.

Defining stigma

There exists a large and growing body of literature that seeks to define and analyse the nature of stigma, not only in relation to HIV, but also in relation to other stigmatized conditions, such as leprosy, epilepsy, TB and various forms of physical deformity and mental illness. One landmark study that dates back to the early sixties, highlights the role of stigma in societies to confirm the “normalcy” of the majority through the devaluation of the “other”.³ This analysis is further developed in a recent study that describes how stigma can be used by dominant groups in communities to legitimize and perpetuate inequalities, such as those based on gender, age, sexual orientation, class, race or ethnicity.⁴

One definition developed that best encapsulates ACORD’s understanding of the problem and that has informed the approach to the investigation documented in this report is the following:

*“HIV/AIDS-related stigma is a real or perceived negative response to a person or persons by individuals, communities or society. It is characterised by rejection, denial, discrediting, disregarding, underrating and social distance. It frequently leads to discrimination and violation of human rights.”*⁵

As highlighted by this definition, stigma is rooted in individual and societal attitudes and is reflected in behaviours that seriously undermine both the rights and dignity of those affected. As shown by previous research studies and confirmed by ACORD’s own research, stigma is a highly complex phenomenon and is manifested in all spheres of society from the home, the community, the workplace, health settings, as well as often being internalized within the individual. This study is concerned with all these different spheres, all of which impact on the achievement of ACORD’s broad mission to promote social justice and equity, particularly for the poorest and most marginalized groups in so

HIV/AIDS has been identified as one of the four priority themes for ACORD as a whole and at a strategic planning meeting held in 2002, HIV/AIDS-related stigma and discrimination was identified as a key focus area for HASAP.

Aims and background of the study

The two research studies, which constitute the primary focus of this report were undertaken by ACORD programmes in Northern Uganda and in Burundi as part of ACORD’s ongoing work in these countries.

→ Drawing lessons from Uganda

In the case of Uganda, the research evolved from the longstanding relationship with communities where ACORD has been implementing HIV/AIDS interventions for over a decade. The need to explore the issues of stigma and discrimination was discussed and agreed upon with the communities themselves and with ACORD’s local partners, including associations of PLHAs (people living with HIV/AIDS).

→ Drawing lessons from Burundi

In the case of Burundi, the research was part of a joint ACORD/ActionAid project aimed at building capacity to develop gender-sensitive responses to HIV/AIDS that also address stigma and other forms of social exclusion funded by DFID as part of a 3-year SIPAA initiative⁶. ACORD was selected to carry out this research in Burundi on the strength of its strong links with communities and its well established reputation in the use of gender-sensitive participatory methodologies.

→ Lesson sharing: community focus

HASAP, the ACORD HIV and AIDS Support and Advocacy Programme, decided to document the experiences of Uganda and Burundi in order to identify the lessons learnt and share these, not only within ACORD, but also with a wider international audience. Besides providing insights into the forms and manifestations of stigma and discrimination in the two countries concerned, HASAP was also interested in drawing out lessons relating to the methodologies adopted for addressing stigma & discrimination and in highlighting the critical role of communities in the search for answers.

→ Comparing experiences

The study also presented a valuable opportunity for comparing the nature and manifestations of stigma and approaches for dealing with it in two countries: the one - Uganda - with a long history of working on HIV/AIDS issues and often held up as a ‘model’ for other countries in Africa; the other – Burundi - where national efforts to respond to HIV/AIDS are relatively recent.

² Progress Report on the Global Response to the HIV/AIDS Epidemic, 2003. ³ Goffman, E Stigma: Notes on the Management of Spoiled Identity, 1963, New York: Simon and Schuster Inc. ⁴ Parker, R and Aggleton, P, 2003, HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action, Social Science & Medicine 57 (3) cited in Disentangling HIV and AIDS, op.cit

⁵ Definition produced from Stigma-AIDS 2001 discussions and Regional Consultation on Stigma and HIV/AIDS in East and Southern Africa, 2001
⁶ SIPAA is the Support to the International Partnership against AIDS in Africa programme



→ **Development of stigma-reduction strategies**

A key aim of the research was to use it as a vehicle for engaging communities and other stakeholders in a dialogue and reflection on the causes of stigma and discrimination and the ways of reducing or overcoming them.

→ **Internal mainstreaming: promoting a stigma-free environment**

ACORD's recently adopted HIV Workplace Policy includes, as one of its major objectives, the creation of a stigma-free working environment for its staff. It was hoped that the lessons from the research processes involving communities in Burundi and Uganda would yield some valuable lessons that could be applied in the process of implementing ACORD's own HIV Workplace Policy and accompanying training and support guidelines.

→ **Advocacy on Access issues**

As already noted, stigma constitutes one of the major barriers to accessing services and treatment. If the global target of ensuring that 3 million people are accessing ARV treatment by the year 2005 (the so-called '3 by 5' initiative) is to be met, effective strategies for addressing stigma and discrimination must be developed as matter of great urgency. Inadequate involvement of communities in the process of analysis and development of responses has undermined the effectiveness of responses to date. One of the aims of this study was to provide first-hand evidence supporting the case for stronger community involvement in this process.

Outline of the book

Chapter One

Focuses on the research in Northern Uganda. It provides some background information on Northern Uganda, including the HIV/AIDS response and ACORD's work in the region over the last couple of decades up to the present. It then discusses the research aims, methodologies, key findings and highlights some of the follow-up actions taken to date.

Chapter Two

This chapter focuses on the research in Burundi. As in the first chapter, it provides some background information on Burundi, including the HIV/AIDS response and ACORD's previous and current work in Burundi. It then discusses the research aims, methodologies, key findings and recommendations stemming from the research. The final section provides information about key follow-up actions taken to date and further plans developed.

Chapter Three

The third chapter highlights the key findings of both research studies and summarises the major recommendations for addressing stigma and discrimination at various levels.

Conclusion

The conclusion highlights key lessons learnt from the research process and the findings.

Chapter One: Northern Uganda Case Study

Background to the Research

Overview of Northern Uganda

Since independence, conflicts and division among the people of Uganda have continued based on religious, political and ethnic or regional differences. However, since 1986, when His Excellency Yoweri Museveni came to power, most of the country has enjoyed economic and political stability. By contrast, the North has continued to be beset by the effects of armed conflicts waged by rebel groups, in particular the Lord's Resistance (LRA), both within Uganda and from across the border in Southern Sudan. These conflicts have centred on the districts of Gulu, Kitgum and Pader.

The impact of conflict

Over the last 20 years, Northern Uganda has experienced a complex web of conflict and insecurity linking all the three sub-regions of Acholi, West Nile and Karamoja. The ongoing conflict has disintegrated social and economic infrastructures, especially in the Acholi sub-region. The impact on the communities has been substantial with more than 800,000 persons internally displaced and forced into so-called 'protected' villages. In addition to loss of life and property and general economic decline, abductions, rape and sexual violence have become commonplace, thereby further aggravating HIV/AIDS vulnerability. Local governance has been weakened leading to the disintegration of basic social services. Social services have also suffered as a result of the diversion of a large proportion of national revenue to meet the rising cost of the conflict in the North. With the rising toll of conflict and HIV/AIDS-related sickness and death, it is families and, women in particular, who have to bear the full burden of care.

Some areas have suffered from intermittent drought, while the border areas with Sudan have been affected by the rebel activities of the Lord's Resistance Army (LRA). In Karamoja, cattle rustlers and other armed robbers have been operating with impunity. Violent resource-based conflicts over water, land and livestock between the Karamajong and their neighbours are common. All these conflicts have led to the proliferation of small arms and light weapons that have become major threats to the lives and security of the civilian population. Banditry and general insecurity characterized by robberies, ambushes and cattle rustling, are threatening the very fabric of societies, compounded by other social problems like poor basic infrastructures, roads, inadequate transport services, education, health and sanitation facilities.

The prolonged armed conflict has also resulted in the destruction of infrastructures like schools and health centres, which have been prime targets for the rebels. The insecurity in the rural areas has affected extension services. Teachers and health workers have been displaced to towns for safety leaving the communities with limited access to basic social services. This is reflected in the poor indicators for health services⁷, education, water and sanitation with a direct impact on the quality of life for the poor. In the West Nile sub-region, the refugee influx from southern Sudan is placing a huge burden on infrastructures, the environment, social services and an economy already weakened by past internal conflicts. In addition, conflict-affected areas cannot attract any private investment and some

⁷ For example, the infant mortality rate in Gulu district is the highest in Uganda at 172/1000



donors are reluctant to fund long-term development programmes due to the insecurity, thus widening the economic disparities.

The impact of HIV/AIDS

Almost every homestead in Northern Uganda has tasted the bitterness of the loss of a useful member of the household due to HIV/AIDS. The HIV prevalence rate in Gulu went up to 11.9% in 2002 from 11.3% in 2001. In Kitgum and Pader, the rate is 9% compared to the national rate of 6.1%⁸

Poverty and the limited access to education and services in IDPs, result in significantly increased vulnerability to HIV/AIDS for the camp population. The strong links between poverty, conflict and HIV/AIDS were highlighted in research carried out by ACORD in 1999, which highlighted the intensification of behaviours (particular among the military) linked with increased HIV/AIDS vulnerability. These include: widespread rape; higher incidence of unprotected sex, especially in the case of mobile soldiers; an increase in the number of sex workers networking with the soldiers, who are the only people with a secure source of income; and early marriages due to fear of abduction.

The combined impact of HIV/AIDS and conflict on families and communities in the region has been devastating: deep reductions in family income; steep rises in medical and health care expenses; and declining agricultural production, land use and crop cultivation, resulting in food insecurity and dependence on food distributions by the World Food Programme. Moreover, the growing number of children orphaned by HIV/AIDS and/or the conflict is placing an immense burden on communities who are finding it increasingly difficult to care for them.

Government Response to the HIV/AIDS Crisis

HIV/AIDS has been on the Ugandan scene since 1982 when the first AIDS case was identified in Rakai District. Since then, HIV has continued to spread unabated, reaching epidemic levels. It is estimated that to date, over 1 million Ugandans have died of HIV/AIDS related illnesses. Over 1.5 million are currently living with HIV/AIDS and the number of children orphaned by HIV/AIDS is estimated at over 2.3 million.

Despite the grim situation presented above, the Uganda Government has been at the forefront in fighting the HIV/AIDS scourge since 1986 when the national HIV/AIDS control programme was set up under the auspices of the Ministry of Health. Later in 1990, the Government realized that HIV/AIDS was a broader developmental issue, with multiple dimensions, requiring a multi-sectoral response. It was on this premise that Uganda adopted the multi-sectoral strategy against HIV/AIDS, launched in 1991. The multi-sectoral approach encourages the active contribution of stakeholders in the public and private sectors, as well as civil society, to the national effort to combat HIV/AIDS. To operationalize this strategy, the Uganda AIDS Commission was created by an act of Parliament in 1992. The Commission has developed a 5- year HIV/AIDS strategic framework that provides guidelines aimed at ensuring consistency and quality of responses.

To ensure a coordinated response, the Uganda AIDS Commission has facilitated the formation of an HIV/AIDS Partnership forum in all districts for the civil society organizations as well as the District

HIV/AIDS Task Force for the political leaders and the line ministries. Government has opened up sentinel surveillance sites in 30 districts out of 55 districts where blood screening is done without cost.

In terms of progress, Uganda is widely acclaimed as a success story in reducing the prevalence rate of HIV during the last decade, from over 30% to approximately 6% to-date. This success has to a large extent been attributed to the high-level political commitment and leadership, openness about the problem, and encouraging a multiplicity of actors to respond. It is worth mentioning that PLHAs have been central to the whole process, playing an active role in HIV/AIDS prevention and mitigation activities, and to some extent in policy formulation. In terms of care and support, the Government recently formulated a national policy on provision of ARVs, and plans are underway to start providing free ARVs to PLHAs. The role played by donors cannot be over-estimated in terms of the resources committed to addressing HIV/AIDS.

The above achievements notwithstanding, HIV/AIDS remains a big challenge to contend with in Uganda, leaving no room for complacency. Despite the declining trends in HIV prevalence at the national level, some geographical areas affected by conflict, especially Northern Uganda, still experience high levels of HIV incidence and prevalence and thus require more efforts. Care and support needs for PLHAs remain largely unmet. Stigma and discrimination against PLHAs, still prevails and seriously undermines the quality of life of PLHAs. The orphan problem has grown to an extent that the traditional extended family system of caring for orphans is reaching or, in many cases, has reached breaking point.

That said, there are many lessons that Uganda has to offer others and there is a crying need for documenting and disseminating best practices to be shared as widely as possible, especially with those who have more recently started on the long journey of developing effective responses to HIV/AIDS.

ACORD's work in Northern Uganda

ACORD has been actively engaged in efforts to reduce mass poverty in Northern Uganda over the last two decades. ACORD's interventions in three districts (Gulu, Nebbi and Moyou/Adjumani) have been aimed at increasing the access of poor and marginalized communities to basic health care, safe water and education, as well as food security and disposable income. ACORD's work has also included raising awareness of HIV/AIDS and providing care, counselling and support for those infected and affected. Key strategies employed by ACORD for achieving its main objectives have included capacity- building of local organizations and working in partnership with the communities involved and others. Over the years, ACORD's work in this region has been supported mainly by NOVIB, the EU, Comic Relief and DFID.

ACORD Northern Uganda Area Programme(NUP)

In 2002, the different branches of ACORD in the North were merged to form a single Northern Uganda Programme with a new focus on the promotion of durable peace in the region, as well as the continuation of its previous work on poverty reduction. The new programme covers the districts of; Adjumani and Moyo in the West Nile sub-region; Gulu, Kitgum and Pader in the Acholi sub-region; and Nakapiripirit and Kotido in the Karamoja sub-region. The main activities include: support for community-based peace-building and conflict- resolution initiatives that uphold local values; the strengthening of



partnerships between local governments and civil society for effective service delivery; increasing community involvement in influencing decisions, development priorities and policies at the local level; promoting youth participation in local planning and peace initiatives; reinforcing the survival strategies of vulnerable groups; and promoting communities' involvement in reducing the spread of HIV/AIDS and mitigating its impact at household and community levels. ACORD's work focuses primarily on the most vulnerable groups, including: in and out of school youth, displaced youth, nomadic youth, victims of war, especially sexually abused women, landmine victims, formerly abducted youth returnees, war disabled, people living with HIV/AIDS (PLHA) and their immediate caregivers; and child mothers, particularly those who have become mothers due to forced marriages, abduction and rape. The promotion and facilitation of community-focussed research and advocacy constitute integral elements of ACORD's overall strategy.

The programme as a whole is expected to contribute to the achievement of the Government's Uganda Poverty Eradication Action Plan (PEAP), in particular the strengthening of good governance and security, one of four broad policy goals identified under the plan. In all, it estimated that over a million people in Northern Uganda will gain access to HIV/AIDS education, care, support and enjoy the benefits of a vibrant local economy when the long-awaited peace arrives.

The Research Findings

In 2003, NUP singled out the issue of HIV/AIDS-related stigma as a key focus for their HIV/AIDS research for that year. It was agreed that research on this theme would first be carried out in Gulu Municipality and that further research would follow later in the year or early 2004 in the other districts of Kitgum and Moyo/Adjumani, which would build on lessons learnt from the experience in Gulu.

Aims of the research

The following aims for the research were identified:

- To identify the extent of HIV-related stigma and discrimination in the community and explore the feelings and reactions of PLHAS and their carers and close family members.
- To analyse the socio-cultural factors that contribute to such attitudes and behaviours towards HIV, including the impact of gender relations.
- To explore how affected and infected families cope with stigma and discrimination.
- To identify opportunities for action against stigma and discrimination.

Research methodologies

The research was carried out in 2003/4 using a mix of the following three methodologies:

- In-depth interviews with respondents
- Focus Group Discussions with key informants
- Direct observation.

The Gulu research was carried out by 2 ACORD researchers working with two researchers from ACORD's partner, the Redeemed Bible Way. Other research facilitators included: 4 community counsellors from the sub-county; 4 PLHAs from 2 PLHA associations (Dyeretek and Dii Cwinyi). In Kitgum, the research was conducted by 3 ACORD researchers, 3 from St. Joseph's Counselling Unit and 2 from the Uganda Red Cross Volunteers and 3 from Meeting Point, a local NGO implementing VCT and home-based care.

Survey sample

In Gulu: Respondents

- People Living with HIV and AIDS (PLHAS)- 90.
 - Affected Families/care givers – 57.
 - Traditional/opinion leaders, Teachers, Local Leaders - 27
- Total: 46 male, 127 Female = 173

In Kitgum:

- 40 PLHAS (20 male and 20 female)
- 40 carers (20 male and 20 female)
- 20 members of the local council and traditional leaders

In Moyo:

- 32 PLWA (16 males, 16 females)
- 17 Care takers (12 males, 5 females)
- 5 Focus Group Discussion with each 10 members (30 males, 20 females)
- 10 groups of key informants with 6 persons per group (30 males, 30 females)

Survey findings

Responses of People Living with HIV/AIDS (PLHAs)

→ Reactions to discovery of own status

70% of the survey respondents had been aware of their sero-status for 5 years or longer. 80% had been tested at the regional hospital and the rest found out after losing a partner or a child to HIV/AIDS. In one case, the person had been living with the virus for 15 years. On hearing of their sero-status, most PLHAS felt frustrated, annoyed, shocked and distraught.

"I felt life was very useless. I felt lost and I was blaming myself." (33 year old female PLHA)

Only 10 of the 90 people interviewed in Gulu said their reaction was one of acceptance. A few (2) attempted suicides and one person said that he wanted to poison the entire family. One PLHA (a man) said that, upon discovering his HIV status, the first thing he did was to send his wife away. Most of the respondents said they eventually were able to cope with the idea, however, most cried during the interviews when recalling what they had felt at the point of discovering their status.

Here are some of the comments made during the interviews:

".....I felt annoyed, I decided to keep quiet right from the counselling room. I thought about my children..."

"... I was frustrated, got depressed and I would get constant headaches....."



→ **Reactions of partners and others**

Reactions of partners differed, but there appears to be evidence of husbands blaming and rejecting their wives more so than vice versa. For example:

“... I tested my self, and told my husband. He denied. Later both of us went together and tested my husband. He was found positive. My husband was annoyed and being an ex-soldier, he went back to the army and since then I have not seen him...”

“...I tested my self and found I was positive, my husband later tested himself and he was positive too, therefore he decided to go and kill the one he thought had infected him. I managed to convince him and he didn't do it”

In all, 80% of female PLHAs were still caring for their spouses and children, compared with only 20% of male PLHAs. Other PLHAs said their husbands only asked them where they got the sickness from, and in most cases blamed them, their wives, for having brought the disease. Only one-woman respondent said her husband's reaction showed acceptance and understanding. He said:

“let us be calm and face death”.

In the case of children, many reacted badly based of lack of information and knowledge about the implications of HIV. For example, children made comments like:

“...But Mummy you are still fat...”

“...Mummy you are a fool. Daddy died of witchcraft...”

Some simply despaired. For example, a 13 year-old daughter ran away from home and got married and a 14 year-old boy tried to commit suicide, using rat poison (luckily, he was found in a swamp and saved in time).

Some children had quite a pragmatic reaction. A ten-year old boy asked to be tested after his mother died of HIV. Another made the following comment:

“...Mummy if you die I will make sure I keep the rest. I won't even get out of the house...” (12-year-old boy)

In general, it was found that as the sickness progresses; the reaction of family members worsens.

→ **Coping mechanisms**

Many PLHAs have developed positive coping mechanisms, such as the following examples cited during the interviews of respondents:

- Eating well and going for regular medical check ups
- Avoiding sex, alcohol and too much work
- Turning to God for spiritual healing

- Becoming activists and educators within their communities
- ‘Coming out’ to families and relatives
- Joining groups of PLHAS
- Opening a bank account in the name of their children

→ **Experiences of stigma**

80% of PLHAs said they are haunted, mostly by self-stigma. Respondents related examples of stigma experienced in practically every sphere of life from the home, the community, the workplace, school and health settings.

In the home: 70% said that they experienced less stigma at home than in the community. However, in many cases, PLHAs are stopped from sharing the bathroom, basins, cups or plates, with other family members.

In the community at large (school, health settings, marketplace, etc): Stigma against PLHAs, even young children with the virus, is widespread and, in some cases, quite extreme. For example, some PLHAs reported cases of neighbours beating children and insulting them with comments like ... *“get away, you look like an AIDS patient.”* A high percentage of PLHAs interviewed mentioned that the perception of people in the community is that all PLHAs ‘pretend’ so as to get free things from supporting organisations like World Vision.

The testimonies of female PLHAs also highlight the discrimination suffered by PLHAs who try to sell their goods in the market place:

“I was chased away from my market stall where I used to sell small fish.”(female PLHA in Kitgum)

“People do not want to buy the local brew that I make so I have to take it for sale at a relative's place where people do not know about my sero-status.” (female PLHA in Kitgum)

The attitude and rudeness of health workers was a key concern for many of the PLHAs interviewed. Many PLHAs also reported cases of mishandling and refusal to attend to them by medical personnel. Several examples were given of health workers who, after realising the sero-status of patients, put their pen down and walked away and/or refused to attend to them.

“When we reached Bobi Health centre, the health worker said I am about to die and why should they still take me to the hospital...”

Even PLHA activists working with communities to prevent the further spread of the virus, experience stigma and discrimination from within their communities as illustrated by this example:

“ Because of my status I can no longer mix with my fellow youth. Their parents stop them from coming to my teaching centre” (youth peer educator)



Newspaper opinion pages and radio programmes are also responsible for spreading negative and discriminatory attitudes.

→ **Stigma experienced by friends and family members of PLHAS**

90% of respondents testified that communities regularly insult the families of PLHAS and accuse them of surviving on free things. It was pointed out that the widows and orphans of people that have died of AIDS often experience heavy discrimination, especially at the funeral of their loved ones. In the Acholi tradition, at a funeral there is a time for introduction, during that moment, mothers in laws and fathers in law can give a specific type of look, which may suggest something like:

“So you are the one who killed my daughter/son eh?”

Such looks can leave widows and orphans feeling very traumatised and stigmatised. Respondents also pointed out the way in which priests can reinforce stigma and discrimination. For example, at funerals pastors frequently make the subject of immorality the centrepiece of their sermon and use their sermon as an opportunity to preach about ‘immoral’ behaviour in a way that is obviously intended to sound as a criticism and judgement of the bereaved family. Moreover, relatives often start discussing things like the future of the children and the division of the late person’s personal goods while the funeral is still going on!

Carers said the problem of “bad language and finger pointing” is one of the biggest challenges in care. Insults from neighbours and landlords are appalling. One respondent had this to say:

“My self and the patient are always discriminated against. Our neighbours don’t want to wash after us in the same bath room...”

Carers provided the following examples of the kinds of things said about them and PLHAS by others in the community:

- *Look at them, if that patient dies; we wonder what your family will eat, since you are used to free food from World Vision.*
- *Please hurry and bath quickly before they pour all their ‘slim’⁹ in the bathroom.*
- *Do not get fire from their place; they might prick you with the virus.*
- *Who told you to get the virus; it is your prostitution that earned you the virus.*
- *That one is a living corpse.*

→ **Responding to stigma**

When asked what they are doing to help overcome the stigma and worries of clients, respondents said:

- Showing love.
- Drawing closer to patients especially when they are in critical conditions
- Encouraging them to go for counselling
- Keeping them active, creative and engaging them in work like knitting.
- Making them turn to God
- Helping them with their chores.

Gender differences

The research confirms that there are differences in the way men and women with HIV/AIDS are perceived, respectively by the opposite sex. These differences reflect patriarchal cultural norms prevalent in Acholi culture. The findings reveal that there is a tendency for men to blame women and vice versa.

What men say about women:

- She looked for it, now she has got what she wanted.
- At least women stay longer when they have HIV.
- The women are going to finish the men.
- They are the ones who bring the disease.
- The woman should be chased away since she is the one who brought the virus.

What women say about men.

- Men want to inherit widows whose husbands die of AIDS.
- Drunkenness makes men have sex with women in any way they like
- If he had died, I would have rested. He nags me a lot.
- Men are womanisers - that’s why they contract the virus.
- They should not keep on spreading the virus.

→ **Gender differences in dealing with stigma**

For the most part, PLHAS feel powerless and unable to defend themselves in the face of such abuse and discrimination. Most said they deal with it as follows:

- Keeping quiet
- Praying to God
- Suppressing their feelings of anger
- Ignoring others and turning to activism

Some differences were found in the ways men and women respond to stigma, with women being more likely to turn their hurt and anger inwards, while men were more likely to turn it outwards. 70% of female respondents said that if they learnt that people are talking about them, they would simply shrug and probably say they are neither the first nor the last people to die. Others said they got very depressed, and wanted to die, and they felt very isolated and frustrated.

By contrast, the male respondents expressed feelings of anger and revenge. In a few cases, male PLHAS decide to take their revenge by deliberately spreading the virus. Others get the urge to kill or rape.



Personal Case story: double discrimination

Esther is a middle aged lady with 2 children living in an IDP camp in Kitgum district. She went for an antenatal test at St Joseph's hospital in Kitgum where the government has introduced PMTCT services. She accepted to be registered for that service because her pregnancy was already six months .

She went back and told her husband about the new service at the Hospital, but the husband, without asking any question went out and came back with a pregnant pig and hit it on the head using an ax. The pig died instantly. He said: " what happened to the pig will happen to her if the HIV/AIDS result will be found positive".

Esther took courage after two weeks and went for the test. When she found that she was HIV positive, she fainted and was hospitalised and put on a drip for three days. She then went straight to her parent's home where she is still living in fear to date..The community counsellor visited her and got this story. She is planning for a divorce and the parents have encouraged her to take legal proceedings for fear that she may be killed like the pig

She has lost much weight, is anaemic and looks very confused

There were, however, some exceptions where women refused to remain passive in the face of unfair stigmatisation. For example, one woman whose husband was constantly telling her to leave his house "because there is no grave space for me in his compound" got so angry with him that eventually, she left his home and now lives with her parents.

Analysis of causes

In the focus group discussions and individual interviews, respondents discussed their views on the factors contributing to stigma and discrimination in relation to PLHAs and those associated with them. A number of issues were raised:

→ **Cultural factors:**

Traditionally, in Acholi land, sicknesses whose causes were not clearly understood, such as leprosy, were regarded as **Gemo** (evil spirit) and as such, a person suffering from such sicknesses would be isolated and forced to live in/near the rubbish pit. Often their food would be thrown at them and nobody would drink from the same cup or eat off the same plate as them.

Acholi attitudes to male and female sexuality also come into play. While men can have as many women as they want, women who have more than one sexual partner are viewed as prostitutes. Since HIV/AIDS is linked with sexual promiscuity, HIV positive women are, heavily stigmatised and they are always blamed even if their husbands die first. Attitudes to women also depend on their reputation before falling sick.:

"If the community perceived that you were a woman of dignity, it is considered a misfortune to have acquired HIV. But if you were a stubborn girl people will abuse you!"(Comment from an elder during a Focus Group Discussion)

Many of these traditions survive today. For example, in Acholi culture, it remains important to ask the cause of death even after the medically examined cause. The elders identified this as one of the factors that may cause discrimination.

→ **Ignorance**

One of the main reasons identified for stigma and discrimination is ignorance. In particular, ignorance about the modes of transmission of the virus. Many people believe it can only be transmitted sexually. This link between HIV and sex gives rise to strong moralistic views and a culture of 'blaming' those who get sick. For example, when asked about their views on the insults hurled against PLHAs, some elders responded:

"...those are not bad words, we would only wish to remind them of their deeds, so that they can reflect on it as they die..."

Ignorance about rights, such as the inheritance rights of women and children are also a factor. For example, 'property grabbing' of women and children whereby the house and property of the deceased are taken by the in-laws.

"...You find that even before the burial, the sisters of the husband and the older co-wives are fighting for the bank book, while the widow and the orphans are seated watching, it is very bad, such incidences one can not forget..."(Councillor)

On the question of widow inheritance, the elders said that it is no longer a big problem except in situations where people are ignorant and not aware at all and also in the event of forceful inheritance by the clan. They added that what is going on now is that people are going back to the former traditional Acholi custom of inheriting children and not wives.

→ **Lack of training and resources**

There is also widespread ignorance on how to treat and care for PLHAs. Lack of training and resources is also a key factor affecting the behaviours and attitudes of teachers and health workers.

→ **Design of NGO programmes**

The way in which aid agencies target and deliver goods and services can also aggravate the problem of stigma. As noted above, one of the most common insults hurled at those infected and/or affected is that they are living off 'free' things. This is a reference to the various types of material support provided by World Vision, namely: maize meal, sugar, beans, blankets, salt; hospital-milk (especially for malnourished children); clothes for burials; and a little cash. When many families and children are in desperate need of such support due to the long-standing conflict and its devastating impact on family



income and food security, it is hardly surprising that others are resentful that such support is reserved strictly for those suffering from HIV/AIDS. Moreover, the fact that food distribution is carried out in the open and widely publicised for all to see and hear about, further aggravates the stigmatisation of PLHAs and their families.

→ **The media**

The media and, in particular, newspaper coverage of HIV/AIDS issues is often indiscriminate, unconcerned about accuracy and deliberately or inadvertently helps to spread misinformation and bias among readers as illustrated in the example of a piece that appeared in one of the main Ugandan national papers last year.

ARMY plans HIV test

The commander of Kadogos polytechnic school at the Army's 2nd division in Mbarara, Major Ndema, plans to have all students screened for HIV/AIDS soon. He was chief Guest at the anti- AIDS show staged at the school. "I am not ready to educate people who are going to die soon....I will sort out and teach those who are not going to die of HIV/AIDS because AIDS is sure death for people who are ignorant"

He added: "Even dogs and cats and elephants are sexually disciplined, they mate at the right time with the right partner, unlike humans"

He added: "some of you when you see skirts around, you start falling in love, please tell me the number of Ugandans who have been buried for not having sex"

Lastly he said soldiers should only die in war.

(The Monitor 24th February 2003)

Follow-up actions and recommendations

The research findings have been discussed and analysed in various settings by different actors. These discussions have focussed on looking at the policy and programming implications of the research and on the ways in which the interest and momentum gained through the research process can be effectively sustained and channelled into concrete actions that will contribute to the reduction of stigma and discrimination in society.

Community recommendations:

One of the first actions taken by ACORD after the Gulu research was completed was to organise meetings in research sites and invite community members, NGOs, teachers, health workers, local council and district government representatives and traditional leaders to participate in a discussion of the findings. The meeting generated much discussion and a number of recommendations were put forward.:

- The head teachers of secondary schools agreed that debates about HIV/AIDS issues should be organised in the schools.

- There should also be HIV/AIDS training for division councillors – both to enhance their own awareness and to train others in the community.
- The speaker of Pece Division moved a motion that councillors should set bye- laws against stigma and discrimination and also censor and ban all video shows with sexual acts/films within their divisions.
- Communities should be encouraged to show love to PLHAs and support them, both materially and morally.
- Councillors should introduce and help to enforce laws to punish those who are guilty of finger pointing and those who use bad language.
- There is a need to train and facilitate more counsellors at the village level.
- NGOs should help and encourage more clients to come out and live positively.
- Intensive counselling should be provided to PLHAs to enhance their self-esteem, thereby reducing the impact of stigma in the community.

In Moyo/Adjumani, the research findings were disseminated and discussed during the district HIV/AIDS partnership Forum meeting. This 3-day workshop was attended by District Leaders, the Chief Administrator's office, the Political Secretary for Health, and representatives of all NGOs implementing HIV/AIDS. One of the key follow-up actions decided upon was to bring together all traditional cultural leaders in the district to review the question of culture. This resolution arose out of concerns discussed during the course of the meeting about the impact of the influx of Sudanese refugees in the area on traditional cultural norms in the West Nile region. It was felt that these issues should be reviewed and the links between HIV/AIDS stigma and discrimination should be explicitly addressed and recommendations developed for reducing the negative and enhancing the positive impact of culture in this sphere.

Staff recommendations

The staff of ACORD's Northern Uganda Programme also met to share and discuss the findings. As part of this exercise, they reflected on the problems and discussed a range of solutions for tackling these problems. These are summarised below.

1. ISOLATION/SOCIAL EXCLUSION AND SELF-STIGMA

Problem:

PLHAs are isolated and socially excluded, often leading to internalisation of stigma and low self-image

Solutions:

- Encourage PLHAs to join the solidarity groups and associations
- Use appropriate IEC (Information, Education and Communication strategies) to reach others (drama, radio, messages)
- Encourage PLHAs within an area to share their experiences with people living in that area
- Encourage home visits by trained counsellors to counsel PLHAs
- Use methodologies, like role play
- Target teachers
- Home-based care
- Use youth-oriented media, such as Straight Talk and Young Talk
- Establish social clubs in schools, eg anti-AIDS Clubs
- Use debates to discuss the issues
- Refer PLHAs to available services, eg ARVs and VCT



2. CULTURAL PRACTICES

Problem:

- Many cultural norms and practices contribute to the spread of stigma and discrimination

Solutions:

- Target cultural institutions for awareness-raising
- Link infected and affected communities to legal institutions to defend their rights
- Encourage positive cultural coping mechanisms (eg building huts for widows, rotational farming, etc)
- Use appropriate IEC to raise awareness in schools and communities
- Provide education on HIV/AIDS for communities
- Empower communities to write wills
- Sensitise communities and women on women's rights
- Use cultural songs to deliver positive messages
- Discuss research findings and follow-up actions within NGO forum
- Involve local leaders in addressing HIV/AIDS

3. RELIGIOUS BELIEFS/TEACHINGS

Problem:

- Religious teachings and preachers reinforce stigma

Solutions:

- Support spiritual healing
- Work with Christian-based organisations (like CHAPS)
- Promote counselling by the church for bereaved families
- Work with Muslim organisations (eg Muslim Women's Group) to reach the Muslim community
- Use retired priests (eg Anglican priests) to reach others

4. GENDER INEQUALITY

Problem:

- Men are allowed to have more partners
- Women are seen as subordinates/property of men
- Women are seen as prostitutes
- Women not allowed to express their views
- Women do not have decision-making power

Solution:

- Educating the community on gender and HIV/AIDS using gender-sensitive methodologies, such as Stepping Stones¹⁰

5. NGO SUPPORT PROGRAMMES

Problem:

- The community becomes jealous of the support provided to the infected/affected families

Solution:

- Co-ordinated interventions/strategies among stakeholders who target PLHAs including caretakers
- Target groups, rather than individuals

6. MEDIA COVERAGE

Problem:

- Inappropriate messages on HIV/AIDS, prevention and care, eg. "AIDS kills" or "AIDS has no cure"

Solution:

- HIV/AIDS messages should always be pre-tested to ensure they are appropriate before being broadcasted
- Messages should address myths, as well as facts about HIV/AIDS
- Most IEC materials should be translated into local languages

7. LOCAL LEADERS

Problem:

- They lack adequate information on HIV/AIDS issues

Solution:

- Leaders should be targeted for HIV/AIDS information
- They should be encouraged to undertake more initiatives in support of PLHAs
- Encourage positive messages from the leaders

Staff meeting held in Gulu, April, 2004

Bye-law to prevent discrimination

In one of the local divisions where the research was discussed, the councillors resolved to introduce a bye-law to outlaw and punish stigma and discrimination in the municipality. This is a lengthy and bureaucratic process and, at the time of writing, has not yet been completed. However, it is hoped that if this initiative proves successful, others will follow suit. While it may not be possible to stamp out all forms of stigma and discrimination in this way, this initiative has sent out a strong message to communities that such attitudes will not be tolerated and this will also help to increase the confidence of PLHAs and encourage them to speak out against abuses of their dignity and rights.

Use of drama and role-play

Drama is a powerful and effective tool for addressing HIV/AIDS-related issues and ACORD works closely with many drama groups and provides them with capacity-building and other kinds of support to enhance their work. To date, the focus of most drama groups is on awareness-raising. However, following on from this research, ACORD has been exploring ways of adapting drama-based methods, such as role play for dealing specifically with HIV/AIDS-related stigma and discrimination. A consultant with extensive experience of using role-play in a variety of settings in the UK to tackle related issues, such as sexual harassment, was invited to share these methods with some of ACORD's partners, including associations of PLHAs working in the district. ACORD will encourage the implementation of these tools and work with partners to monitor their effectiveness.

Dealing with stigma among ACORD staff

One of the off-shoots of the research on stigma in communities is to heighten awareness of stigma, not only in the communities where it works, but also within the organisation itself. Working towards the creation of a stigma-free environment is central to the HIV Workplace Policy that has recently been



approved for the whole of ACORD. It is also a key aim of the NUP's Critical Illness Policy. However, one year after this policy was introduced, there was no take-up of the benefits provided, such as access to VCT and ARVs. A survey of staff views and attitudes undertaken at the time revealed unexpectedly high levels of stigma within the staff. For example, over 50% of staff questioned expressed the view that HIV is linked to immoral behaviour. Thus, it became clear that, unless such attitudes were addressed, the policy would fail to meet its primary objectives, namely - to defend the rights of employees and ensure they have access to accurate and unbiased information. The issue of stigma and discrimination is currently being addressed through formal HIV/AIDS awareness-raising sessions as well as informal discussions and debates. These processes have already had an impact. Two members of staff have come forward to claim benefits. Free condoms placed in bathroom areas and in people's offices need regular replacement. In addition, the general atmosphere in the workplace has changed. For example, sex, condoms, death and other 'taboo' subjects are openly discussed and shared amongst the staff.

Further actions

The findings of the research have implications for many actors involved in the effort to respond to HIV/AIDS in Northern Uganda. Most key actors were present at the dissemination meetings in Gulu and Moyo/Adjumani and it is hoped that they will take back the issues discussed within their own organisational settings leading to action aimed at addressing some of the problems raised. In Kitgum, the feedback process has been held up by the merging of the IDP camp, but a feedback meeting is expected to be held soon. A wide range of stakeholders will be invited to take part in the discussions and development of recommendations for action. The results of the research in all the three districts will also be disseminated at the national level and used as a tool for influencing national level policy.



CARPP (Community AIDS Resource Persons of Pabbo) members at Pabbo Camp for the Displace, Gulu District, April 2004

Chapter Two: Burundi Case Study

Background to the Research

Burundi is one the poorest and most overpopulated countries in Sub-Saharan Africa with a surface area of 27,834 sq kms and an estimated population of over 7 million that is rising at an annual rate of 2.9%. According to the UNDP Human Development Report 2003, Burundi ranked 173rd out of 175 countries. Over 90% of the population live in the rural sector and the economy is based primarily on subsistence agriculture. With average income per head of population estimated at \$14, 60% of the population is living below the poverty threshold in Burundi and closer to 80% in some rural areas. These levels of poverty have been exacerbated by the war, which in the decade between 1993 and 2003, resulted in over 200,000 deaths and the displacement of over one million people.

ACORD's Work in Burundi

ACORD began working in Burundi at the time of the crisis and developed a programme for the social and economic reintegration of people rendered vulnerable by the conflict and the war, initially in the province of Cankuzo in 1994 and later in 1999, in Bujumbura town. In the year 2000, a new programme was developed based on participatory community development in collaboration with the Government of Burundi and IFAD (The International Fund for Agricultural Development) in the four Provinces (Gitega, Karusi, Kayanza and Cibitoke). 2002 also saw the birth of a programme to promote gender equality and social inclusion, followed soon after by the development of a programme supporting local peace-building initiatives. All these different elements form part of the framework programme aimed at 'creating an environment conducive for participation and the reconciliation of divided communities in Burund'i. It is through these programmes that ACORD is contributing to the reduction of HIV/AIDS in Burundi. HIV/AIDS is systematically mainstreamed into it all its activities with poor communities and in all the zones where it works.

National Response to HIV/AIDS

The many political, economic and social problems faced by the country, added to existing cultural factors provide a fertile breeding ground for the spread of HIV/AIDS. The average sero-prevalence rate for adults aged 15 years and over is estimated at 3.6%, making Burundi the 15th in Sub-Saharan Africa. After many years of procrastination, a great many actors from the grassroots to the top of the government hierarchy have now come together to confront the epidemic. The National Council for AIDS Control (CNLS) was created in 2002. The CNLS is a decentralised structure charged with responsibility for coordinating HIV/AIDS activities throughout the country. In the same year, a Ministry for HIV/AIDS was established within the Presidency. Most national HIV/AIDS efforts are funded through bilateral aid, the World Bank and some foreign NGOs.

The civil society sector is also very active and committed to the struggle against HIV/AIDS and state efforts are complemented by numerous civil society initiatives. However, all these efforts cannot suffice in the face of the rapid spread of the pandemic and the scale of suffering caused in its wake.



The Research Findings

Aims of the Research

The overall purpose of the study was to analyse the extent of the problem of HIV/AIDS-related stigma and discrimination in Burundi and, on the basis of the findings, develop proposals for dealing with it.

The specific aims included:

1. To identify the underlying causes
2. Identify the ways in which stigma and discrimination are manifested in the society, focusing in particular on the issue of rights
3. To highlight the ways in which the problem is compounded by gender norms and relations and the specific ways in which women are affected
4. To identify the impact of stigma and discrimination on the feelings, behaviour and quality of life of PLHAs, their carers and close family members.
5. To assess the strategies PLHAs use to cope with stigma and discrimination.
6. To analyse the impact of stigma and discrimination on government programmes relating to HIV/AIDS
7. To identify opportunities for action and make recommendations for addressing the problem

The Research Methodology

The fundamental methodology was based on the principle of the ‘participatory approach’ aimed at taking account of the views of a broad cross-section of the population and ensuring that the views of all relevant actors are expressed openly and freely.

Recruitment and training of researchers

The research was conducted by ‘animators/researchers’ who comprised PLHAs recruited from the National Association of PLHAs of Burundi, which has seats in all the provinces and communes, and the SWAA (the Society for Women and AIDS in Africa) of Burundi. Animation sessions were held to develop interview guides for the ‘animators/researchers’ based on the terms of reference and training sessions were provided covering the aims and methodology of the research.

Selection of research sites

The selection was based on 5 criteria: geographic location; sero-prevalence; location in relation to rebel and transport routes; location relative to borders with other countries; degree of urbanisation. The study covered 5 provinces in the North, South, Centre, East and West (Muyinga, Gitega, Makamba, Ruyigi and Bujumbura Town). The first three were selected on the grounds of their location in the North, the worst affected in terms of sero-prevalence due to their proximity to the Tanzanian border. The latter two were selected because they are a rebel route and, as such, badly affected by acts of sexual violence perpetrated by the rebels. The sites included both urban and rural areas. Within each province, the survey was carried out in the capital of the province and the surrounding areas.

Data-collection

The study was based on primary and secondary data.

Secondary data was collected through libraries and resource centres visited by arrangement with representatives of government departments, including government ministries, other NGOs, community-based organisations, PLHA associations and religious orders or leaders.

Primary data was collected by means of a face-to-face survey. A questionnaire and interview guide were developed for this purpose. The following methodologies were used:

- a) **Community-based discussions:** open sessions in the community were held to discuss the problem and collect people’s views on the issue.
- b) **Focus group discussions:** separate discussions with groups of PLHAs, people affected by HIV – carers, partners and children; and members of relevant government structures as follows:

PLHAS	12
AIDS orphans	3
Men and women	20
Displaced	3
TOTAL	38

- c) **Questionnaire-based individual interviews:** A total of 264 people were interviewed using a cluster sampling method to include the following categories of people in the population:

- PLHAs
- Family members
- AIDS orphans
- Local, traditional and religious leaders
- Members of AIDS units
- Displaced persons

In all, a total of 644 people were involved as respondents in the research.

Data management and analysis

Both qualitative and quantitative data were generated. Quantitative data were inputted using ISSA (Integrated System for Survey Analysis) and processed and analysed using SPAA (Statistical Package in Social Sciences). The qualitative data were ordered by theme and by category of respondent.

Research Findings

Historical and cultural roots of prejudice and discrimination

Stigma and discrimination against particular groups, in particular the poor and physically infirm, have always existed in Burundian society. For example, it was common for lepers and people with smallpox to be isolated and placed in quarantine. Notions of ‘good’ and ‘beautiful’ are promoted through family values and the education system, as also the notion of ‘respectability’ linked to moral virtues and



physical beauty. Girls who became pregnant before marriage were a taint on the family honour and were rejected and cast out. Thus, the links between HIV/AIDS and immorality on the one hand and also with sickness and death can be seen to account in large part for the disapproval and lack of compassion meted out to PLHAs and their families. In contemporary society, these attitudes are reinforced by media sensationalisation and religious emphasis on morality and sexual abstinence. The absence of legislation to protect the rights of PLHAs means that acts of discrimination go unpunished.

Attitudes towards PLHAs

The study revealed high levels of stigma associated with HIV/AIDS. 54% of respondents said they think that someone with HIV is not a normal person. The following are some examples of the derogatory ways in which PLHAs are viewed by many people in the society:

“People say that PLHAs are rotten and they refuse to even give them something to drink.”
“It is better to have an arm amputated or be a beggar than to have AIDS.”

Words used to describe HIV/AIDS include: *“the plague”* or *“filthy epidemic”* and PLHAs are called *“insects”* *“flies”* or *“animals”*.

HIV /AIDS and PLHAs are commonly associated with death: *“he’s finished”* *“a walking corpse”* *“at death’s door”*. Linked to these associations is the idea that people should keep their distance and avoid contact with PLHAs: *“Someone with HIV is a carrier of misfortune and should be avoided at all costs”*.

Negative attitudes towards PLHAs are also based on associations made between HIV and sexual immorality: *“PLHAs are sexual misfits, prostitutes or philanderers.”* Prostitution is viewed as a serious violation of social norms and values and prostitutes are, by definition, considered to be ‘anti-models’ in society.

Such attitudes are used to justify the social marginalisation and exclusion of PLHAs from most forms of normal social interaction with others as evidenced by the responses of many of those interviewed:

- 41% agreed that PLHAs should not be allowed to go to mass
- 14% said they should not be allowed to participate in public feasts
- 5% said they should be isolated at school
- 4% said they should be isolated at work

The children and friends and relatives of PLHAs are also marginalized. For example, children are forbidden to enter the homes of PLHAs or play with their children outdoors. Even at school, children are often isolated, both by their teachers and by their peers. These attitudes are found, not only amongst the population at large, but even among family members. PLHAs are often kept in isolation within their own homes and ‘hidden’ from the outside world.

The view that it is not worth spending money on PLHAs was also widely shared by respondents:

- 54% said that family goods should not be sold to pay for anti-retrovirals (ARVs)
- 27% said that it was not worth spending a lot of money on caring for PLHAs

The main justification for these views was that the cost of treatment is prohibitive and could lead to family ruin whilst there is no definitive cure for HIV/AIDS. However, some respondents were in favour of using family savings to send patients for treatment abroad.

Awareness of stigma and discrimination

The existence of stigma and discrimination is widely recognised by all sectors of society. 73% of opinion leaders and 58% of survey respondents attested to the fact that HIV/AIDS-related stigma is widespread. However, although 67% of PLHAs recognised its existence, only 37% declared that they had personally experienced acts of stigma and discrimination. This is probably due to the fact that many PLHAs are not open about their sero-status and another factor is that people do not usually speak badly about PLHAs in their presence and/or they employ coded messages when passing judgement or discriminating against PLHAs. Another survey finding was that more women than men (44% versus 29%) reported having experienced discrimination. Besides the fact that perceived sexual immorality is more frowned upon by the family and society where women are concerned, it may also reflect that women are more likely to admit it and express their feelings than men are.

Self-stigma

Many PLHAs have internalised these negative attitudes and behaviours towards them with the result that many have developed a very negative self-image and even practice discrimination against themselves:

- 24% of PLHAs said that they should be isolated from others
- 23% said they should have their own bedding and separate eating utensils and clothes

Forms of discrimination and denial of fundamental rights of PLHAs

The vast majority of respondents upheld the basic rights of PLHAs to health, education, employment, support, protection and access to property. Despite this, the study found disturbing evidence of discriminatory practices and behaviours towards PLHAs who are frequently denied these basic rights.

For example, it is not uncommon for landlords to impose unreasonable rent rises in order to force PLHAs out of their homes. Many PLHAs are also denied access to employment and those already in employment are often dismissed when their HIV status is discovered. In the workplace, examples were also given of PLHAs being demoted, re-deployed without consultation and subjected to other ploys aimed at forcing them out of their jobs. Isolation and marginalisation by colleagues is also common and even those who do not overtly discriminate, implicitly do so by turning a blind eye to those that do.

In relation to health care, most PLHAs reported being treated coldly by health workers and several cited examples of having been refused medical treatment on the grounds that *“medicines are reserved for people who can be cured.”*

Certain groups are particularly vulnerable. These are:

- **AIDS widows:** many widows are denied their property and inheritance rights and, in many cases, widows are forcefully ejected from the marital home.



→ **AIDS orphans:** the most widespread form of discrimination against AIDS orphans is isolation from the wider community. It is difficult to find homes for these children, particularly younger ones who are assumed to be HIV positive, and many have to be placed in institutions. Older children, particularly girls who can be used to carry out domestic tasks and children of both sexes with inherited goods are easier to place in homes. However, the families who take them in frequently expropriate the inheritance and goods left to these children, refuse them their right to schooling and in other ways exploit them. The situation is more acute in the case of AIDS orphans who are HIV positive because foster parents can look forward to accessing their properties sooner. AIDS orphans who are HIV positive also experience discrimination within the family as testified by one of the orphans who participated in a focus group discussion:

“Even when they agree to adopt us, we are usually served from a separate platter, we have our own cup, our clothes are kept separate and we sleep alone.”

→ **Relatives of PLHAs:** the most common forms of discrimination are isolation and lack of respect. Parents are often subjected to insults and accused of being bad parents and bearers of the virus themselves. Siblings are subject to finger-pointing and taunted by peers who say they are also condemned to die soon. All family members are branded as belonging to a ‘bad family’.

→ **Women and girls:** On average, three out of every four respondents stated that women with HIV are more stigmatised than men. Gender discrimination is also apparent with reference to access to medical care. When asked who in the family should get priority for treatment, only 9.1% said it should be the mother compared with 28% who said the father and 36% who said the children (the rest were undecided). There was also a preference for boys, compared with girls, on the ground that boys are breadwinners and girls are more likely to be forced into prostitution.

Analysis of Causes

The study sought to get people’s views on the prime causes or main motors of stigma and discrimination in the society.

→ **Cultural values:** 46% of respondents felt that family education and cultural values are the main driving factors. These values put a high premium on fidelity, modesty, reserve and honesty and, in the eyes of many, the behaviour of PLHAs is deemed to be in breach of these valued attributes. These perceptions of PLHAs are also reinforced by HIV education in schools.

→ **Religion:** religious teachings was also identified as a key vector of stigma by 11% of respondents. Priests and religious leaders preach abstinence and fidelity as the only means of avoiding infection. Those who become infected are viewed as ‘transgressors’ who have “eaten the forbidden fruit”. In the eyes of the church “the punishment for sin is death”, hence AIDS is equated with divine retribution.

→ **HIV/AIDS Programmes:** 16% of respondents thought that programmes targeting PLHAs also contribute to stigma. People seen to be going for VCT or other services are assumed to be HIV positive and are stigmatised by others. That said, PLHAs decried the lack of government programmes, which forces them to appeal to the kindness of others for help:

“The Government has abandoned us...aid destined for us is diverted for the purchase of vehicles. There are many meetings, but we do not see the results. The little help we do get is thanks to SWAA.”

→ **PLHAs:** 8% of respondents said that PLHAs themselves contribute to stigmatisation on account of their low self-image and their tendency to isolate and blame themselves for their condition.

→ **The media:** The role of the media was only mentioned by 2% of respondents. False or inaccurate media reporting of the disease was considered by them to be a key factor contributing to stigma.

→ **Absence of legislation upholding rights of PLHAs:** As succinctly put by one of the PLHAs respondents:

“We will always be stigmatized because we have no legal recourse.”

The impact of Stigma and Discrimination on PLHAs and their families and carers

Impact on PLHAs

→ Impact on feelings and behaviour

According to PLHAs, the most common way in which they respond to the stigmatising attitudes of those around them are: feelings of regret (27%); resignation (27%); defensiveness (18%) and guilt (11%).

In addition, some respondents mentioned that denial is quite widespread. For example, AIDS widows sometimes re-marry and have children in order to convince others they are not positive. Also, examples were given of employees who try to prove they are still fit for work by over-stretching themselves and working longer hours than their colleagues. Some PLHAs accuse others of being HIV positive so as to feel less alone. Others hide themselves away in their home or move to another locality where they are not known. Some deliberately set out to infect others as way of exacting revenge on society for their own misfortune.

Those who resign themselves to their situation frequently turn to God and spirituality and build up their self-esteem through living positively and showing understanding to those who show contempt towards them:

“When others discriminate against you, but you do not discriminate back, you feel better within yourself.”

Joining associations of positive people is another way in which PLHAs are able to develop inner strength and solidarity mechanisms.

Impact on families and carers

According to respondents, the main effect of stigma on families is discouragement and despair. Others spoke of increased solidarity that develops, both within the household and with others in the same situation.



Impact of Stigma and Discrimination on HIV/AIDS Programmes

The research also sought to analyse the impact of stigma and discrimination on government HIV/AIDS programmes in Burundi.

- **Programmes aimed at reducing 'risky behaviours':** These include condom promotion and the promotion of VCT. Stigma undermines such programmes because people are afraid of being assumed to be HIV positive if they use condoms or go for VCT. People may also avoid being seen at community awareness and education sessions in case they are assumed to be HIV positive. Fear of stigma also discourages people who have tested positive from declaring their status and in the case of those who know they are positive, many continue to behave as if they were not.
- **Social marketing of condoms:** Take-up is very limited, in large part for the reasons mentioned above.
- **VCT:** as stated above, people are reluctant to be tested and prefer not to know their sero-status. Take-up of counselling is also undermined for the same reasons.
- **STD treatment:** Many people are aware that STDs may be a precursor of HIV and consequently avoid seeking treatment so as to avoid the risk of being found positive.
- **Care of AIDS orphans:** Stigma is a factor that contributes to the difficulty of finding families willing to take in AIDS orphans. Similarly, stigma impacts on the quality of care provided and AIDS orphans are often discriminated against within these families.
- **Prevention of Mother to Child Transmission:** Women often refuse to go for treatment or take measures to reduce the risk of transmitting the virus to their baby in order to avoid being stigmatised by the community.
- **Micro-credit programmes:** Credit for groups of PLHAs is often used for petty trade purposes. However, it is common for people to refuse to buy goods sold by PLHAs in the market or elsewhere, thereby undermining the success of these small enterprises.

According to this analysis, failure to address stigma and discrimination appears to be seriously undermining the effectiveness of programmes aimed at preventing the spread and mitigating the impact of HIV/AIDS and these programmes are not reaching a high proportion of those who could potentially benefit from them.

Views on what should be done

Survey respondents were asked to rank in order of priority the strategies required to reduce levels of stigmatisation and discrimination against PLHAs in the community. Their responses are shown in the table overleaf:

Respondent views on Strategies need to tackle stigma and discrimination

	All respondents	PLHAs
HIV/AIDS awareness-raising	78%	84%
Establishing a law against stigma and discrimination	74%	92%
Introduction of sanctions against those who discriminate	71%	78%
Increasing access to ARVs	9%	6,7%
Joining PLHA associations	2%	0%
VCT	1,6%	0%

In relation to awareness-raising, it was stressed that this should specifically address the question of HIV/AIDS stigma and discrimination. A programme of training of community-based educators should be established to ensure that messages are clear, uniform and free from bias and prejudice.

As the table below shows, support for a law banning discrimination was most strongly backed by PLHA respondents:

Those in favour of a law banning discrimination against people with HIV/AIDS

Opinion leaders	72%
People living with HIV/AIDS	92%
Others	69%
TOTAL	74%

In relation to ARVs, it was noted that access to ARVs will help to improve the health of PLHAs, thereby reducing stigma and also enhancing the incentives for people to be tested. However, measures to ensure equal access to ARVs for women and for poorer sections of the community are needed to reduce the risk of discrimination against these groups.

Other suggestions that emerged through the questionnaires and through the focus group discussions, include:-

- **Community care and support:** community members should be encouraged to show care and understanding and support PLHAs and their families through home visits and so on. This would help to reduce the problem of low self-esteem and social marginalisation of PLHAs within their communities.
- **Home visiting by doctors:** a number of respondents expressed the view that doctors should visit patients in their own homes on the grounds that:

“If people see that doctors are concerned, this would help to reduce stigma and discrimination against AIDS patients and they would be willing to share meals with them without fear of getting infected.”



→ Setting a good example: Government officials should be open about their status and should promote positive, non-discriminatory attitudes towards PLHAs thereby setting a good example for communities.

Follow-up actions

At the time of writing, ACORD Burundi is in the process of developing a strategic action plan to follow up on the findings of this research. This process is still in its early stages, but some steps have already been taken. These are described below.

Preliminary dissemination of findings

A report bringing together the research findings was produced and ACORD Burundi organised a workshop to present and discuss the findings. Participants at the workshop included representatives of local and international NGOs, PLHA associations, government ministries, members of the National Assembly and a representative from the Presidency of the Republic. The report findings were discussed and the following comments and follow-up proposals were made:

- A law to uphold the rights of PLHAs is long overdue
- PLHAs have duties and responsibilities, as well as rights
- Should PLHAs who deliberately spread the virus be penalised?
- The research mainly focussed on poor sectors of society. Similar research is needed to analyse stigma and discrimination within the affluent classes (businessmen, decision-makers, and so on)
- Research should also be carried out in specific sectors, such as schools, professional circles, prisons
- A separate study examining response strategies in more detail should be undertaken
- The role of PLHAs in developing response strategies should be emphasised
- Micro-credit and income-generating schemes should be more broadly targeted to cover vulnerable groups and people affected by HIV, so as to avoid stigmatising PLHAs
- Attention should be focussed on the content and tone of awareness-raising campaigns and messages to avoid aggravating the problem of stigma
- Need to stress access to other kinds of care and treatment, including treatment of opportunistic infections, not just ARVs

Rights 'Observatory'/Network

At the feedback workshop, one of the proposals discussed was the establishment of an 'Observatory of the Rights of People Infected and Affected by HIV/AIDS' whose functions would include promoting awareness of the rights of PLHAs and providing support to those who have been victims of discrimination. A number of organisations, including NGOs and PLHA associations volunteered to form a nucleus that would meet again in order to explore this idea more fully.

To date, this Nucleus has met twice. The first meeting focussed on the mission and key objectives of the Observatory and the second one on its structure and management. The following agreements were reached:

• *Mission and specific objectives*

The mission of such an Observatory is the promotion and protection of the rights of people living with HIV/AIDS and the global objective is to contribute to the reduction of stigma and discrimination against PLHAs.

Specific objectives include:

- ✓ Systematic analysis of cases of violation of rights of people infected and/or affected by HIV/AIDS
- ✓ Support for victims of stigma and different forms of HIV-related discrimination
- ✓ Raising public awareness and undertaking advocacy around the rights of PLHAs

• *Structure and Membership*

- ✓ In the long-term, the Observatory should be established as a Network in order to permit the broadest possible participation of concerned groups and individuals in the country. However, in the short-term, it should be set up as Common Project funded as a development project with clearly defined activities implemented by a small number of dedicated NGOs.
- ✓ The Observatory should be independent of the government. However, relations and cooperation with state structures will be promoted in order to access material support and enhance coordination with government policies and services.
- ✓ Decentralisation is a critical feature: establishment of access points in community-based centres and/or other mechanisms will be explored for ensuring that everyone can access this service, including people living in remote rural areas.

• *Other features*

- ✓ Training and capacity-building of staff should be a high priority to enhance the quality of service provided, as well as enhancing the credibility and effectiveness of the Observatory

To date, 14 organisations, including the main association of PLHAs in Burundi, are behind this proposal. It was agreed that ACORD Burundi should serve as the Coordinating Agency in the first phase of the Project prior to its establishment as a broader network.

Further dissemination of the research

The first phase of dissemination was focussed primarily on government bodies and other NGOs. The next phase will entail the organisation of research feedback sessions at the community level. Community-level discussions will be held using gender-sensitive participatory techniques to encourage the widest possible level of participation in the discussions. These discussions will focus on analysing both the causes and consequences of stigma and discrimination from the perspective of community members and on soliciting the views of different groups within communities on what should be done to address the problems highlighted.

Follow-up training and advocacy

The results of these discussions will be formulated into recommendations and used as the basis for carrying out advocacy actions targeting a range of actors, including central and local government, service-providers (in particular schools and health providers), the media, religious groups and others. As part of this advocacy, ACORD is planning to develop a training workshop that will be aimed at government officials, NGO staff and others to provide them with tools for integrating stigma awareness and reduction strategies in programmes and responses at all levels.



Chapter Three: Summary of Key Findings and Recommendations

This chapter brings together the main findings of the research and recommendations based on the research carried out in both countries. It also draws out some of the key lessons learnt from the research process itself and the ways in which these can contribute to efforts to improve HIV/AIDS-related policy and programming within the NGO sector and beyond.

Key Findings

Causes of stigma and discrimination

Study respondents in both countries identified the following factors as key contributors to the existence and perpetuation of stigma in society:

→ **A Ignorance and fear**

Lack of information and understanding of the causes and symptoms of HIV/AIDS give rise to myths and stereotypes that surround the disease and these, in turn, incite irrational fears and anxieties linked to contact with people who are or are thought to be infected. In particular, the association of HIV/AIDS with promiscuity and death lies at the heart of most forms of stigma and discrimination.

→ **A Cultural norms and values**

HIV/AIDS is widely perceived to transgress cultural norms and values that stress fidelity within marriage and abstinence for youth. Gender norms based on ideal notions of women's role and behaviour in society contribute to the disproportionate stigmatisation of female PLHAs, who are often accused of being prostitutes and/or bearing the greatest responsibility for spreading the virus.

→ **A Religious teachings**

While religion and spirituality usually provide a source of comfort and solace for PLHAs, religious teachings often contribute to the culture of 'blaming' PLHAs by the association made between sex and immorality.

→ **A Absence of legal sanctions**

The lack of legislation to promote and protect the rights of PLHAs creates an environment in which blatant forms of prejudice and discrimination can be practised with impunity.

→ **A Lack of rights awareness**

This situation is compounded by lack of awareness of the rights of PLHAs, such as the right of widows to inherit the property of their deceased spouse.

→ **A Targeting of PLHAs for special assistance**

Programmes that target PLHAs, such as micro-credit and support for income-generating activities and support aimed at AIDS orphans and their families in the form of food rations, help with school fees, clothing, and so on, often fuel resentment among other community members resulting in increased stigmatisation.

→ **Media coverage**

Inaccurate and biased media reporting is often responsible for reinforcing myths and stereotypes about HIV/AIDS and spreading negative images of PLHAs.

Manifestations and consequences of stigma and discrimination

→ **Social isolation and exclusion**

PLHAs and those most closely associated with them are rejected, isolated and excluded from most forms of social interaction, in community gatherings, the workplace, places of worship, the marketplace and even within their own homes.

→ **Abuse and insults**

PLHAs and close family members and carers are also frequently subjected to insults and abusive behaviour, such as finger-pointing.

→ **Internalisation of stigma**

The negative attitudes and behaviours of those around them are internalised by PLHAs resulting in feelings of helplessness, despair, lack of motivation and self-hatred. These feelings can sometimes lead to aggressive acts of revenge and deliberate spreading of the infection.

→ **Denial of rights**

The rights of PLHAs to education, health care, housing, employment, income and inheritance, other rights are frequently violated, thereby seriously undermining their ability to live positively and participate on an equal footing in the life of the society.

→ **Undermining livelihood strategies**

Refusal to trade with PLHAs undermines their ability to support themselves, resulting in further impoverishment and increased dependence on others.

→ **Non-take up of services and treatment**

Fear of stigmatisation and discrimination acts as a strong disincentive to take preventive measures (such as condom use), find out and/or disclose their status and access available services and treatment (such as VCT, treatment of STDs, workplace benefits, ARVs and so on). As a result, the effectiveness of government and NGO programmes in the areas of both care and treatment is seriously undermined.

Key recommendations

The following are the main recommendations for dealing with HIV/AIDS-related stigma and discrimination that were put forward, either by individual survey respondents or in the focus group discussions held in the context of this research. They also include recommendations put forward by ACORD staff and others involved in the compilation and analysis of the research findings.

Challenging attitudes and perceptions

Many of the recommendations were aimed at addressing the issue of negative attitudes resulting from



the lack of accurate information and the influence of certain cultural norms and practices.

→ **Awareness-raising and sensitisation**

The provision of accurate, unbiased information about HIV/AIDS was generally agreed to be the most critical first step in addressing stigma and discrimination. Respondents in both countries also stressed the importance of producing information in local languages and using a range of non-verbal forms of communication, including radio, drama, song, dance, and so on.

→ **Challenging gender discrimination**

Respondents in both countries reported that in most cases, women with HIV are more stigmatised and more vulnerable to discrimination than men. This was linked to traditional stereotypes and forms of cultural conditioning where women's sexuality is equated to promiscuity and women with HIV/AIDS are condemned as prostitutes. Using methodologies, such as Stepping Stones, which encourages both men and women, young and old, to challenge such stereotypes was put forward by ACORD staff in Gulu as an effective way of reducing the level of discrimination faced by girls and young women.

→ **Sensitisation of religious leaders, media, schools and so on**

Religious leaders, journalists and school teachers, all exert an enormous influence on how people think. In both Northern Uganda and Burundi, the research provided numerous examples of the ways in which religious teachings, the school curriculum and newspaper articles often aggravate the problem of stigma and discrimination. Thus, sensitisation and training, including guidance on acceptable terms for referring to PLHAs, should specifically target these groups.

Promoting and defending the rights of PLHAs

The vast majority of respondents, not only PLHAs themselves, their carers and family members, but also local level leaders, service providers and ordinary community members felt strongly that HIV/AIDS-related stigma and discrimination is a fundamental human rights issue and needs to be addressed at that level. The following recommendations are specifically aimed at tackling the problem from a rights perspective.

→ **Introducing legislation enshrining the equal rights of PLHAs within the framework of the law**

Despite international conventions and declarations, such as UNGASS, that embrace the principle of equal rights for PLHAs and oppose all forms of discrimination on the grounds of HIV/AIDS status, in practice very few places have introduced laws or other legal mechanisms for penalising offenders. Thus, there is a need for the national governments to introduce such legislation. Municipal bye-laws and other local level initiatives should be encouraged in order to strengthen and reinforce national law, as in the case of the initiative taken by one of the sub-county divisions in Northern Uganda.

→ **Legal rights awareness**

Even where rights have already been established by law, such as the rights of widows to property inheritance, many people are not aware of their rights and are not, therefore in a position to defend them. Enhancing women's knowledge of their rights and their capacity to defend them will help to raise women's status, thereby also reducing the degree of stigma and discrimination that disproportionately affects women and girls in society. Thus, groups providing legal support and advice to women at local and national level and other similar initiatives, should be supported.

→ **Community-based monitoring and rights promotion mechanisms**

Legislation on its own is limited in its capacity to defend the rights of PLHAs. In Burundi, it was proposed that an effectively coordinated network of NGOs, CBOs and PLHA associations should be established to monitor violations of rights and support victims of abuse. The network should function at the local, as well as national level, targeting all groups, including those living in remote, marginalized areas. The role of the network would also include promotion of legal rights awareness and advocacy at local and national levels.

Increasing the voice and influence of the PLHA community

Many of the recommendations put forward proposals aimed at promoting the role of PLHAs themselves in developing and implementing strategies for reducing stigma and discrimination, including self-stigma by PLHAs.

→ **Encouraging PLHAs to go public and give personal testimonies**

In Uganda, as elsewhere, PLHAs have played a significant role in educating the public on what it means to live with HIV/AIDS, and the need for people to be compassionate towards PLHAs. They have also helped to give HIV/AIDS a human face, bringing it closer to the minds of people. For many years, ACORD has worked closely with PLHAs and their associations in Uganda to provide awareness-raising to communities and this has contributed to reducing levels of stigma and discrimination. The media, schools and others should also provide a platform for PLHAs to make their voices heard.

→ **Working with and supporting PLHA associations**

Networks and associations of PLHAs are an important source of mutual support and solidarity, which helps to increase the self-confidence and enhance the self-image of PLHAs, both as a group and as individuals. Many such associations are also involved in advocacy to promote the rights of their members and of PLHAs in general. Working in partnership with and supporting PLHA associations was identified as a key strategy for addressing stigma and discrimination in both Uganda and Burundi.

Integration of stigma awareness in programming and service delivery

The research highlighted the fact that failure to take account of stigma and discrimination not only undermines the ability of government and NGO programmes to reach their targets, but can even aggravate the problem in some cases. This issue demands a re-think of how we design and deliver programmes aimed at supporting people infected and or affected by HIV/AIDS in order not to reinforce stigma and discrimination.

→ **Re-design programmes to avoid the need for targeting**

Programmes targeted at particular groups, such as those providing food rations for families affected by AIDS or other forms of support for AIDS orphans, were found to increase the stigmatisation experienced by these children and their families on account of the feelings of resentment from other community members. In addition, take-up of services, like VCT, is undermined due to fear of being branded as HIV positive. Respondents in Uganda and Burundi proposed various strategies for addressing this problem, such as targeting groups, rather than individuals and delivering a range of services in the same setting so that people who go for testing and/or counselling can not be easily identified. Ultimately, however,



this problem can only effectively be tackled through enhancing levels of awareness and understanding and in this way reducing the level of stigma associated with HIV and AIDS.

-----> ***Community-based support***

Respondents in both countries felt that providing services within communities and/or in the home could help to address the problem of stigma. In Uganda, it was suggested that more community-based counsellors should be trained to provide door-to-door advice and information, thereby simultaneously supporting communities and providing a good example to others in terms of showing love and understanding to PLHAs, their carers and families. In Burundi, it was proposed that health providers, in particular doctors, should make home visits as a means of helping to reduce community fears based on ignorance and misinformation about the routes of transmission of the virus.

-----> ***Training of policy-makers***

There is also a need for training for those involved in policy development at all levels, from government ministries to NGO programme managers to increase their level of awareness of the problem of HIV/AIDS-related stigma and discrimination and enhance their capacity to integrate this awareness into the design of programmes and policies developed to respond to the needs of those infected and/or affected by HIV/AIDS.

Conclusion

The research has highlighted the fact that overcoming HIV/AIDS related stigma and discrimination remains one of the major challenges to be addressed in the development of effective responses. This is true, not only in Burundi where popular awareness and the government response have only recently emerged, but also in Uganda where the issue of HIV/AIDS has been high on the agenda for nearly two decades. The findings revealed many similarities, both in relation to the causes of the problem and in the ways in which it is manifested in society: in both places, stigma and discrimination are fuelled by fear and ignorance, compounded by religious and cultural norms and values, and they are manifested in all spheres, from the individual and the family, to the community and societal institutions, such as churches, schools and hospitals. Not surprisingly, therefore, research respondents in both countries identified similar strategies for tackling the problem, ranging from awareness-raising to promoting the rights of PLHAs through the law and other means. More importantly perhaps, the research itself in both countries has generated increased awareness of the existence of stigma and discrimination and stimulated concrete actions aimed at addressing the situation. The strategies identified do not address all the problems and much still remains to be done. However, the important thing is that the ongoing search for answers has been set in train and is likely to continue.

In conclusion, therefore, it could be said that one of the most important lessons to be taken from ACORD's experience of facilitating these research processes in both countries, is that the value of such research lies not only in contributing to our understanding of the dynamics of HIV/AIDS-related stigma and discrimination, but equally in its capacity to stimulate a process of critical reflection and action-oriented analysis among the key actors – namely, PLHAs who are the prime victims, policy-makers, service providers, opinion leaders and the community at large, who all have a stake in addressing this problem and promoting a spirit of caring and collective responsibility in supporting those living with the virus and their carers.

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