

# Disentangling HIV and AIDS STIGMA in Ethiopia, Tanzania and Zambia



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change



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ZAMBART PROJECT

KARA COUNSELLING  
"Positive and Fully Alive" ✓

**Illustrations:** Petra Röhr-Rouendaal and children from Zambia.

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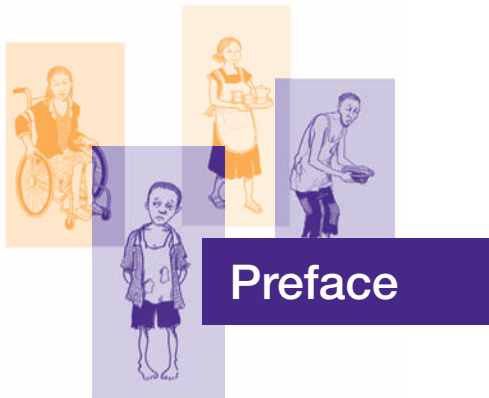
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- The CHANGE project of the Academy of Educational Development (AED) (USA)
- Miz-Hasab Research Center (Ethiopia)
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This is a synthesis report of the findings from studies in Ethiopia, Tanzania and Zambia. For copies of the individual country reports listed below, contact the following:

Kidanu, Aklilu, Hailom Banteyerga and Laura Nyblade. 2003. *Exploring HIV/AIDS Stigma and Related Discrimination in Ethiopia: Causes, Manifestations, Consequences and Coping Mechanisms*. Addis Ababa: Miz-Hasab Research Center.

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Mbwambo, Jessie, Gad Kilonzo, Peter Kopoka and Laura Nyblade. 2003. *Understanding HIV-Related Stigma in Tanzania*. Dar es Salaam: MUCHS.

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Bond, Virginia, Levy Chilikwela, Sue Clay, Titus Kafuma, Laura Nyblade and Nadia Bettega. 2003. *"Kanayaka"—"The Light is On": Understanding HIV and AIDS related Stigma in Urban and Rural Zambia*. Lusaka: Zambart Project and KCTT.

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# Executive Summary

The International Center for Research on Women (ICRW), in partnership with organizations in Ethiopia, Tanzania, and Zambia, led a study of HIV and AIDS-related stigma and discrimination in these three countries. This project, conducted from April 2001 to September 2003, unraveled the complexities around stigma by investigating the causes, manifestations and consequences of HIV and AIDS-related stigma and discrimination in sub-Saharan Africa. It then uses this analysis to suggest program interventions.

Structured text analysis of 730 qualitative transcripts (650 interviews and 80 focus group discussions) and quantitative analysis of 400 survey respondents from rural and urban areas in these countries revealed the following main insights about the causes, context, experience and consequences of stigma:

1. The main causes of stigma relate to incomplete knowledge, fears of death and disease, sexual norms and a lack of recognition of stigma. Insufficient and inaccurate knowledge combines with fears of death and disease to perpetuate beliefs in casual transmission and, thereby, avoidance of those with HIV. The knowledge that HIV can be transmitted sexually combines with an association of HIV

with socially “improper” sex, such that people with HIV are stigmatized for their perceived immoral behavior. Finally, people often do not recognize that their words or actions are stigmatizing.

2. Socio-economic status, age and gender all influence the experience of stigma. The poor are blamed less for their infection than the rich, yet they face greater stigma because they have fewer resources to hide an HIV-positive status. Youth are blamed in all three countries for spreading HIV through what is perceived as their highly risky sexual behavior. While both men and women are stigmatized for breaking sexual norms, gender-based power results in women being blamed more easily. At the same time, the consequences of HIV infection, disclosure, stigma and the burden of care are higher for women than for men.
3. People living with HIV and AIDS face physical and social isolation from family, friends, and community; gossip, name-calling and voyeurism; and a loss of rights, decision-making power and access to resources and livelihoods. People with HIV internalize these experiences and consequently feel guilty, ashamed and inferior. They may, as a result, isolate themselves

and lose hope. Those associated with people with HIV and AIDS, especially family members, friends and caregivers, face many of these same experiences in the form of secondary stigma.

4. People living with HIV and AIDS and their families develop various strategies to cope with stigma. Decisions around disclosure depend on whether or not disclosing would help to cope (through care) or make the situation worse (through added stigma). Some cope by participating in networks of people with HIV and actively working in the field of HIV or by confronting stigma in their communities. Others look for alternative explanations for HIV besides sexual transmission and seek comfort, often turning to religion to do so.
5. Stigma impedes various programmatic efforts. Testing, disclosure, prevention and care and support for people with HIV are advocated, but are impeded by stigma. Testing and disclosure are recognized as difficult because of stigma, and prevention is hampered because preventive methods such as condom use or discussing safe sex are considered indications of HIV infection or immoral behaviors and are thus stigmatized. Available care and support are accompanied by judgmental attitudes and isolating behavior, which can result in people with HIV delaying care until absolutely necessary.
6. There are also many positive aspects of the way people deal with HIV and stigma. People express good intentions to not stigmatize those with HIV. Many recognize that their limited knowledge has a role in perpetuating stigma and are keen to learn more. Families, religious organizations and communities provide care, empathy and support for people with HIV and AIDS. Finally, people with HIV themselves overcome the stigma they face to challenge stigmatizing social norms.

Our study points to five critical elements that programs aiming to tackle stigma need to address:

- Create greater recognition of stigma and discrimination
- Foster in-depth, applied knowledge about all aspects of HIV and AIDS through a participatory and interactive process
- Provide safe spaces to discuss the values and beliefs about sex, morality and death that underlie stigma
- Find common language to talk about stigma
- Ensure a central, contextually-appropriate and ethically-responsible role for people with HIV and AIDS

While all individuals and groups have a role in reducing stigma, policymakers and programmers can start with certain key groups that our study suggests are a priority:

- Families caring for people living with HIV and AIDS: programs can help families both to cope with the burden of care and also to recognize and modify their own stigmatizing behavior
- NGOs and other community-based organizations: NGOs can train their own staff to recognize and deal with stigma, incorporate ways to reduce stigma in all activities, and critically examine their communication methods and materials
- Religious and faith-based organizations: these can be supportive of people living with HIV and AIDS in their role as religious leaders and can incorporate ways to reduce stigma in their community service activities
- Health care institutions: medical training can include issues of stigma for both new and experienced providers, while at the same time, risks faced by providers need to be acknowledged and minimized
- Media: media professionals can examine and modify their language to be non-stigmatizing,

provide accurate, up-to-date information on HIV, and limit misperceptions and incorrect information about HIV and people living with HIV and AIDS

The complexity of stigma means that these and other approaches to reduce stigma and discrimination will face many challenges, but, at the same time, there exist many entry points and strong, positive foundations for change that interventions can immediately build on.



# 1 Introduction

**M**ore than two decades into the HIV and AIDS epidemic, stigma and discrimination against people who have HIV or are affected by HIV continue unabated. Moreover, the nature of stigma remains an enigma. Fundamental questions remain: what is stigma, from where does it arise, why does it persist despite increasing awareness and knowledge about HIV, and how do we effectively confront it? The study described in this report unravels some of the complexities around stigma by investigating the causes, manifestations, and consequences of HIV and AIDS-related stigma and subsequent discriminatory acts in the context of sub-Saharan Africa. It then uses this analysis to suggest program interventions.

In particular, the objectives of the study were to:

- Disentangle the underlying factors that perpetuate or mitigate stigma;
- Document how stigma is influenced by the context in which it occurs;
- Analyze how stigma and discrimination are experienced by people with HIV and others who are affected by the disease;
- Understand how stigma and discrimination affect access to HIV prevention, testing, disclosure, care, and support efforts; and
- Make recommendations for interventions.

From April 2001 to September 2003, the International Center for Research on Women (ICRW) led this research initiative in three African countries: Ethiopia, Tanzania and Zambia. ICRW's research partners were the Miz-Hasab Research Center in Ethiopia; the Department of Psychiatry, Muhimbili University College of Health Sciences (MUCHS) in Tanzania; and Zambart<sup>1</sup> and Kara Counseling and Training Trust (KCTT) in Zambia. The initiative was funded by the United States Agency for International Development through the Academy for Educational Development's (AED) CHANGE Project, with additional support from the CORE initiative, the Swedish International Development Agency (SIDA), and the Positive Action program of GlaxoSmithKline.

This synthesis report presents the principal findings from the past two years of research. Section 2 describes the current HIV situation in developing countries, particularly in sub-Saharan Africa, and how stigma is relevant. Section 3 gives a theoretical framework for studying stigma. Section 4 describes the study design. Section 5 presents findings related to the underlying causes of stigma, the contextual factors that influence stigma, individual and community experiences of stigma and consequences for programs. Finally, Section 6 provides recommendations for programs and interventions.

<sup>1</sup> A collaborative project between University of Zambia's School of Medicine and the London School of Hygiene and Tropical medicine.



## 2.1 HIV and stigma worldwide

Globally, 40 million people were estimated to be living with HIV and AIDS at the end of 2001. Sub-Saharan Africa is clearly the worst-affected region. With 28.5 million people living with HIV and AIDS (PLHA)<sup>2</sup> in 2001, sub-Saharan Africa accounts for more than 70 percent of all HIV and AIDS cases in the world. Over two million of the three million deaths due to AIDS in 2001 occurred in sub-Saharan Africa. AIDS is now the leading cause of death in sub-Saharan Africa and the cause of a 15-year drop in life expectancy in the region, from 62 to 47 years. New HIV infections are highest among young people, and young women have consistently been found to have higher (in some cases as much as six times as high) prevalence rates of HIV than men of the same age (UNAIDS 2002).

The late Jonathan Mann, former head of WHO's Global Program on AIDS, identified stigma as a "third epidemic" early in the history of HIV (the first two being the hidden but accelerating spread of HIV and the visible rise of AIDS cases). Mann recognized that stigma, discrimination, blame and collective denial were potentially the most difficult aspects of the HIV and AIDS epidemic to address, but also that addressing them was key to

overcoming it (Mann 1987). Stigma still remains one of the most significant challenges in developing countries for all HIV and AIDS programs, across the prevention to care continuum. Stigma increases vulnerability to HIV and worsens the impact of infection. Fear of being identified with HIV keeps people from learning their serostatus, changing behavior to prevent infecting others, caring for people living with HIV and AIDS, and accessing HIV and AIDS services (Bond and Nubani 2000; Nyblade and Field 2000; Tlou et al. 2000; Maman et al. 2001; ICRW 2002a; UNAIDS 2002; Hutchinson et al. 2003). Additionally, stigma intensifies the emotional pain and suffering of people living with HIV and AIDS, their families and caregivers (Castro et al. 1998a; Castro et al. 1998b).

Nonetheless, HIV-related stigma remains poorly understood, particularly in developing countries. While studies investigating stigma have a longer history in developed countries like the US, most of this work has focused on the stigmatizing attitudes of individuals, rather than stigma as a societal phenomenon (Crandall 1991; Crandall and Moriarty 1995). Stigma usually has been studied in the US through self-reported attitudes and hypothetical rather than observed behavior (Herek

<sup>2</sup>We recognize the current debate around the use of the acronym PLHA and appreciate the importance of not referring aloud to persons living with HIV and AIDS as acronyms, but use PLHA here as a means to shorten the text and ease reading.

and Capitanio 1993; Herek et al. 2002). Studying stigma at this level has the effect of treating it as an individual attribute rather than as a social process. A small, but growing body of literature on HIV-related stigma in developing countries has emerged in recent years. This literature looks at the experiences of people living with HIV and AIDS, the forms of stigma encountered, stigma within the workplace and fears of stigma in relation to participation in programs (Castro et al. 1998a; Castro et al. 1998b; UNAIDS 2000a; UNAIDS 2000b; Maman et al. 2001; Alubo et al. 2002; Hutchinson et al. 2003; Nyblade and Field 2000; Bond et al. 2002; ICRW 2002b).

Most recently, literature has turned toward stigma interventions. For example, a study in India is testing whether using a checklist sensitive to the concerns of people living with HIV and AIDS in hospitals (a “PLHA-friendly checklist”) will reduce health care workers’ stigma towards people living with HIV and AIDS (Horizons 2002). Brown and others (2003) recently reviewed 22 evaluated interventions (six in developing countries, 16 in developed countries) that sought to improve attitudes towards people with HIV and AIDS (e.g. Kuhn et al. 1994; Klepp et al. 1997; Fawole et al. 1999), to assess people’s willingness to treat and care for people living with HIV and AIDS (e.g. Lueveswanij et al. 2000; Uwakwe 2000), or to improve the ability of people with HIV or AIDS to cope with stigma (Kaleeba et al. 1997). They found that these interventions had mixed results, though those that fostered direct contact with people living with HIV and AIDS were slightly more effective than others.

Despite this growing body of knowledge, there is still a dearth of studies to help us understand HIV-related stigma and evaluate community-based interventions that address stigma, either as an issue in its own right or as a critical component of other HIV and AIDS programming. We also lack

rigorously tested and widely accepted indicators to measure stigma in developing country contexts, which are needed to assess the extent of the problem in a given locale and to evaluate our efforts to reduce stigma. The study described in this report was conducted to address some of these gaps. It aims to disentangle the complex elements of stigma and the social processes through which it occurs and to identify entry points for interventions.

## 2.2 HIV prevalence and policy in study countries

Ethiopia, Tanzania and Zambia have had differing experiences with the intensity of and response to the HIV epidemic. Table 1 below depicts overall prevalence rates and prevalence rates among women attending antenatal clinics. These two indicators were chosen because they are available for all three countries.

Reported HIV prevalence is lowest in Ethiopia, slightly higher in Tanzania and quite a bit higher in Zambia, where over one-fifth of the population is currently HIV-positive. The prevalence rates obtained from antenatal clinics suggest large urban-rural differences, with urban areas typically experiencing higher HIV prevalence than rural areas. The urban-rural gap in Ethiopia is particularly striking, with almost five times higher HIV prevalence in urban than rural areas.

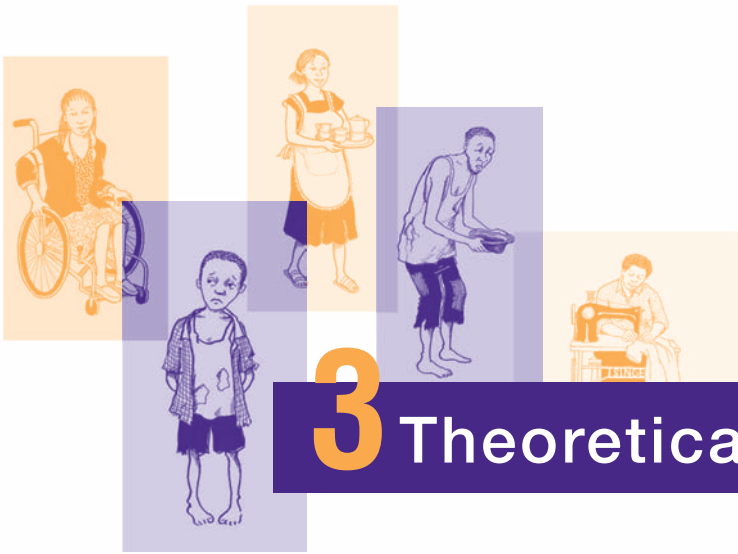
**Table 1: Current Overall HIV Prevalence in Ethiopia, Tanzania and Zambia**

	Prevalence Rate	Prevalence Rate, Women Attending Antenatal Clinics	
		Urban	Rural
Ethiopia	6.5%	14.9%	3.1%
Tanzania	7.8%	17%	14%
Zambia	21.5%	30.7%	13%

Source: UNAIDS 2002

Each of the countries has formulated policy responses to the epidemic. Ethiopia and Tanzania have a national HIV and AIDS policy, strategic plan and a national AIDS body to coordinate the national response. All three countries lack specific legislation against discrimination on the grounds of HIV. Ethiopia's national policy, however, gives some mention to HIV and human rights, and

Tanzania's national policy explicitly reinforces the need for respecting human rights and decreasing stigma and discrimination. Similarly, Zambia has a national strategic plan with clearly identified priorities that emphasize de-stigmatization of HIV and AIDS (UNAIDS and ECA 2000).



## 3 Theoretical Framework

The theoretical framework for this study borrows from research conducted since the 1960s on stigma related to various illnesses, and more recent literature on stigma specifically associated with HIV and AIDS.

### 3.1 Defining stigma and discrimination

The standard point of departure for defining stigma is Erving Goffman's classic study on stigma related to mental illness, physical deformities and what were perceived to be socially deviant behaviors (1963). Goffman describes stigma as "an attribute that is deeply discrediting" and results in the reduction of a person or group "from a whole and usual person to a tainted, discounted one." He goes on to note that by regarding "others" negatively, an individual or group confirms their own "normalcy" and legitimizes their devaluation of the "other."

Expanding on Goffman's work, Link and Phelan describe stigma as a dynamic process occurring within the context of power (2001). This process has four distinct steps. The first three steps seek to divide the "tainted" from the "usual" people by distinguishing and labeling differences; associating negative attributes with those differences; and separating "us" from "them." Building on Link and Phelan's conceptualization, Gilmore and Sommerville describe these three steps in the

process as allowing the others ("them") to be perceived as non-persons (1994). This allows the "us" to distance themselves from the negative attributes of the "others," to justify treating the "others" in negative ways that would be unacceptable if they were one of "us," and to prevent "us" from being treated in the same negative manner. These steps culminate in the fourth and final step in Link and Phelan's process—status loss and discrimination for the stigmatized.

Parker and Aggleton, in turn, suggest that stigma can become firmly entrenched in a community by producing and reproducing relations of power and control (2003). Stigma is used by dominant groups to legitimize and perpetuate inequalities, such as those based on gender, age, sexual orientation, class, race or ethnicity. By doing so, dominant groups effectively limit the ability of stigmatized groups and individuals to resist because of their entrenched marginal status. Furthermore, the stigmatized often accept the norms and values that label them as having negative differences (Goffman 1963). As a result, stigmatized individuals or groups may accept that they "deserve" to be treated poorly and unequally, making resistance to stigma and resulting discrimination even more difficult. Research shows that this internal stigma is manifested in many ways including self-hatred, self-isolation and shame (Alonzo and Reynolds 1995).



Thus, the ultimate effect of stigma, as noted by Goffman, is the reduction of the life chances of the stigmatized through discriminatory actions (1963). Therefore, for the purpose of this work, we do not conceptualize discrimination as separate from stigma, but as the end result of the process of stigma. We define discrimination as the negative acts that result from stigma and that serve to devalue and reduce the life chances of the stigmatized.

### 3.2 Stigma and medical conditions

In addition to an exercise of power, stigma can be a response to fear, risk, or a threat of disease that is incurable and can be deadly (Gilmore and Somerville 1994). The more rapid the spread of the disease and the greater the uncertainty of how the disease is transmitted, the more stigmatizing the response. Epidemics that present an overt threat to the values of a community are especially likely to evoke a stigmatizing response, as stigma is used to “enhance or secure social structuring, safety and solidarity...or reinforce societal or community values by excluding divergent or deviant ones [or individuals]” (Gilmore and Somerville 1994).

Stigma related to medical conditions is greatest when the condition is associated with deviant behavior or when the cause of the condition is viewed as the responsibility of the individual. This becomes particularly strong when the illness is associated with religious beliefs and thought to be contracted through morally sanctionable behavior (Alonzo and Reynolds 1995). Stigma is also more evident when the condition is unalterable, incurable, severe, degenerative, and leads to readily apparent physical disfigurement or to an undesirable and unaesthetic death (Cogan and Herek 1998; de Bryun 1998; Alonzo and Reynolds 1995).

### 3.3 HIV and AIDS-related stigma

HIV and AIDS have all of the characteristics associated with heavily-stigmatized medical

conditions. They are associated with socially “improper” forms of sex and injecting drug use, socially-censured behaviors that are viewed as the responsibility of the individual. AIDS is incurable, degenerative, often disfiguring and associated with an “undesirable death” (Nzioka 2000). It is often incorrectly thought to be highly contagious and a threat to the community at large. The general population, and sometimes medical personnel, are not well-informed and lack a deep understanding of HIV and AIDS. It is no wonder, then, that HIV-related stigma has been particularly challenging to tackle.

Goffman describes three general causes of stigma: physical deformities; moral transgression; and membership of a despised social group, which is transmittable through lineage and can equally contaminate all members of a family (1963). People living with HIV and AIDS almost always are associated with the first two because of the physical manifestations of AIDS and the association of HIV with “deviant” and “immoral” behaviors (particularly sexual “promiscuity” and intravenous drug use). In addition, many people living with HIV and AIDS are members of groups that are already socially marginalized, such as sex workers, homosexuals and the poor. This particular subset of individuals with HIV and AIDS experiences multiple stigmas, with HIV stigma compounding pre-existing stigmas (known as double or compound stigma) (Herek and Glunt 1988; Parker and Aggleton 2003). HIV and AIDS are then used to justify further marginalization of such people, further entrenching deeply-rooted prejudices. Those most likely to experience HIV-related stigma commonly have the fewest resources to cope with and resist it, adding to the difficulty in fighting stigma.

HIV-related stigma is also complicated to tackle because it is dynamic. It changes both as an individual progresses from HIV to AIDS, and as the HIV epidemic evolves in a given community.

Alonzo and Reynolds describe this dynamic nature as the illness trajectory of HIV (1995). The experience of stigma and the strategies used to avoid, minimize, or cope with it change over the course of a single illness trajectory (Alonzo and Reynolds 1995; Castro et al. 1998b).

### 3.4 Linking the conceptual to the practical: the motivation for this study

This study aimed to take the well-developed conceptualizations of stigma and operationalize these ideas into smaller, manageable components that could provide entry points for programmers to reduce stigma. In other words, the approach of this study has been to disentangle the concept of “stigma” conceptualized in the literature. To do so, we have found it useful to think of HIV-related stigma as depending on an interaction of various elements of an individual’s identity in a particular social context. We define these elements as the “who,” “where,” “why” and “what” of stigma.

The “who” refers to an individual’s or group’s identity in a particular location or context (the “where”). For example, a woman’s identity can vary between mother, wife, child, sex worker, or congregation member, depending on whether she

is in her home, her parents’ home, the bar or her place of worship. “Who” can be both the person who stigmatizes or who is stigmatized, acknowledging that one person can be both. Whether or not he or she stigmatizes may depend on the “where.” For example, in the workplace a person may stigmatize a fellow co-worker who is HIV-positive, while at home not stigmatizing his or her own child who is also living with HIV. The “why” refers to the context and causes underlying stigma, for example the norms and values about what is or is not appropriate sexual behavior, access to knowledge about HIV and AIDS, poverty, power structures and social inequity. The “who,” “where,” and “why,” in turn, determine the “what,” or the experience of stigma. Specifically, the stigma experienced by an individual or group, and the ability to cope with and resist it, may be more or less intense depending upon the combination of the “who,” “where” and “why” at a particular point in time.

Our analysis of the data, as well as presentation of results, follows this approach of separately examining different parts of the whole of stigma in an effort to disentangle stigma.



## 4 Study Design and Methods

The project described here studies HIV-related stigma and discrimination in an effort to provide suggestions and directions to programs and policies to tackle stigma. This project was conducted between April 2001 and September 2003. Data was collected by in-country partners, with support from ICRW. The key components of the study are:

- A comparative study in rural and urban communities in Ethiopia, Tanzania and Zambia on HIV and AIDS stigma and discrimination.
- Sub-studies in each country to explore context-specific issues related to HIV and AIDS and stigma.

### 4.1 Comparative community-based studies

Community-based studies in each country gathered information on those who stigmatize, those who are stigmatized, factors that determine the scope and extent of stigma and discrimination and institutional responses to stigma. The research teams in each country, with support from ICRW, developed research instruments based on these major research themes. The teams selected an urban and rural site<sup>3</sup> in each of the three countries for the community-based exploration of HIV-related stigma and discrimination. These communities are

largely poor with high population density in urban areas and limited access to services, especially in rural areas. Employment is dominated by the informal sector in urban areas and subsistence farming in rural areas.

### 4.2 Sub-studies<sup>4</sup>

Each country team chose topics for sub-studies to reflect issues of immediate concern in their communities.

#### 4.2.1 Perspectives of people living with HIV and AIDS (Ethiopia, Tanzania, Zambia)

- **Ethiopia:** Men and women living with HIV and AIDS who belong to a nongovernmental organization (NGO) offering support to people with HIV and AIDS wrote diaries for six months, documenting their experiences with disclosure, interactions with family, community, peers, and colleagues, and how they coped with the illness. They were interviewed by Miz-Hasab Research Center.
- **Tanzania:** MUCHS researchers sought to learn about the experiences of people living with HIV and AIDS with stigma and their experiences as they disclosed their status over time. To this end, MUCHS enrolled voluntary counseling and testing (VCT) clients who were HIV-positive at the

<sup>3</sup> Specific details of the study sites are described in the country research reports.

<sup>4</sup> Methods and findings of the sub-studies are described in detail in the country research reports.

time of VCT and interviewed them over a period of 10 months.

- Zambia:** Zambart researchers followed a selection of households with tuberculosis (TB) patients over time to examine the interactions between stigma surrounding TB and HIV and AIDS in households. Additionally, Zambart and KCTT explored the experiences of children infected with and affected by HIV in the rural area through workshops and in-depth interviews with children.

#### 4.2.2 Health care training facility (Tanzania)

MUCHS interviewers explored HIV-related stigma and discrimination within a health care training setting. They conducted focus group discussions (FGDs) and interviews with nursing and medical students and instructors at a medical training facility to assess knowledge, attitudes, and fears about HIV and AIDS, people living with HIV and AIDS, and care and support of those affected by and infected with HIV.

#### 4.2.3 Language and media content (Tanzania and Zambia)

In Tanzania and Zambia, researchers sought recommendations from linguists, HIV and AIDS experts, historians and theologians on how to talk about stigma in the local languages. The Tanzanian researchers, using the language of the experts with

whom they consulted, then assessed the extent to which people at the community level used similar or different words to understand and describe stigma. This exercise enabled researchers to incorporate a community’s understanding of the expression of stigma into the research design. Tanzanian researchers also analyzed print media to assess whether or not there was a link between language used there and derogatory language used by people in communities when referring to people with HIV and AIDS.

#### 4.3 Methods of data collection

Researchers largely employed qualitative methods to collect data, with the exception of a quantitative survey conducted by Miz-Hasab Research Center in Ethiopia. The combined data set in the three countries included 730 qualitative transcripts (650 interviews and 80 focus group transcripts) and 400 survey respondents. Across the countries and studies, respondents included community members, people living with HIV and AIDS, youth, religious leaders, health professionals, caregivers, educators, employers and NGO staff. The researchers purposively sampled all interview and focus group discussion respondents by sex and socio-economic status. Tables 2 and 3 show methods and sample sizes. More details are available in country research reports.

**Table 2: Data Methods and Samples for Community-Based Studies**

	Ethiopia	Tanzania	Zambia
<b>Study sites</b>	<b>Rural:</b> 1 community in Sheshemene district <b>Urban:</b> 1 community in Addis Ababa	<b>Rural:</b> 2 villages in Kinondoni district <b>Urban:</b> 2 communities in Kinondoni district	<b>Rural:</b> 2 communities in Choma <b>Urban:</b> 2 communities in Lusaka
<b>Comparative Community-Based Studies</b>			
Participatory Research Activities	-	4	3
Key Informant Interviews	15	45	-
Focus Group Discussions	13	21	53
In-depth Interviews	52	47	68
Survey	402	-	-

**Table 3: Data Methods and Samples for Country Sub-Studies**

Sub-Studies	Ethiopia	Tanzania	Zambia
	Urban	Urban	Urban/Rural
<i>Perspectives of People Living with HIV and AIDS</i>	Diaries with 14 people with HIV and AIDS over 6 months; pre-post interviews with each person (28)	Interviews with 179 VCT clients; follow-up interviews with 30* people with HIV and AIDS over a 10-month period	6 rounds of interviews with 13 households with TB patients; 8 workshops, 72 interviews with children
<i>Language and Media Content</i>	-	Reviewed 1 year of back issues in 13 mainstream national periodicals; 33 interviews with lay people	-
<i>Health Care Training Facility</i>	-	18 interviews and 8 focus groups with students and instructors	-

\*Over the course of the study, a significant number of clients died or migrated from the research sites, reducing the sample size and thus the range of experiences documented.

### 4.3.1 Qualitative and participatory research methods

The psychosocial, contextual and behavioral dimensions of stigma and discrimination are better suited to qualitative methods that capture values, attitudes and beliefs, than to quantitative tools. Qualitative methods are highly useful in exploring motivations and underlying factors supporting discriminatory behaviors. Research methods across the three countries included key informant interviews, focus group discussions, diaries, content review and semi-structured interviews. At the onset of the study, participatory techniques (such as transect walks, community mapping, listing of health problems and timelines) were conducted in each of the communities to build rapport and gain insight into the general community layout and structure. The use of multiple methodologies to acquire data ensured triangulation and validation of the findings. N4 software was used to systematically process and analyze the data.

### 4.3.2 Quantitative survey methods

In Ethiopia, Miz-Hasab Research Center investigators felt it critical to have a baseline understanding of the community’s knowledge, attitudes and behaviors around HIV, stigma and people living with HIV and AIDS. Researchers administered a survey questionnaire to 202 rural residents and 200 urban residents who were systematically selected from existing official household lists. The data was entered, cleaned and analyzed using SPSS and STATA statistical packages.

### 4.4 Data collection process and ethical considerations

ICRW and in-country partners gave considerable thought to the selection of research tools to ensure confidentiality, privacy and personal safety of both participants and researchers while studying this highly sensitive issue. We tested our research tools and trained data collectors extensively on these methods to ensure tools were

applied flexibly and were appropriate for the issue and setting. We also provided data collectors with intensive training on HIV and stigma.

Maintaining confidentiality and anonymity of study participants was another key component of

the research process. In addition, each of the research teams gained clearance for the research from the appropriate institutional ethical committee in their respective countries. Prior to each interview, informed consent was obtained from the participants.



The intensive process of training and data collection described above yielded rich information on the dynamics of stigma in the three study countries. We present here some of the key themes that underlie stigma in all three settings. More details on these and additional themes, including rural-urban differences and findings from the sub-studies, are in the country research reports. This section examines the causes of stigma and discrimination, in particular the role of knowledge, attitudes about sex, sin, and morality, and fears of death; the context of stigma, with a focus on socio-economic status, age, and gender; the experiences of stigma; and some programmatic consequences of stigma, specifically, for prevention of HIV, testing, disclosure, and care and support. We also draw attention to evidence of good intentions and non-stigmatizing attitudes and behaviors in the study communities.

### 5.1 Causes of stigma and discrimination

HIV and AIDS are intimately linked with sex and death. Our research shows that stigma around HIV and AIDS persists so tenaciously because it is deeply enmeshed with social and personal views, beliefs, fears and taboos around sex and death. Incomplete and contradictory knowledge of HIV fuels some of these beliefs and contributes to

#### Summary of findings about causes of stigma and discrimination

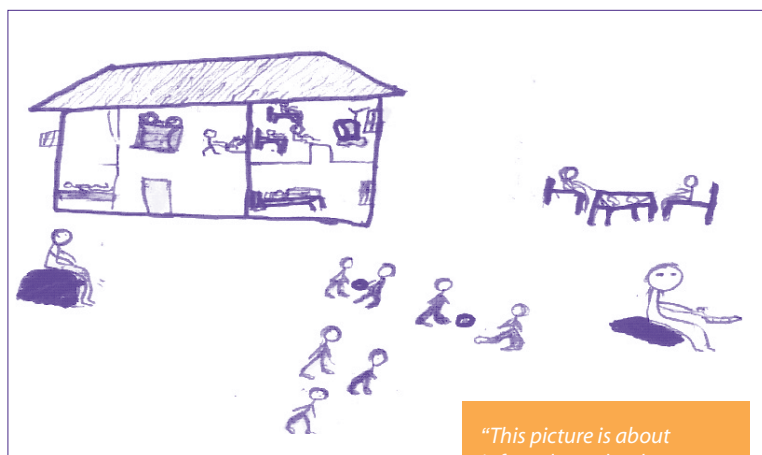
- Most respondents know how HIV is transmitted, but more detailed knowledge of other aspects of HIV and AIDS is incorrect or missing altogether.
- Incorrect knowledge combines with fear of death from HIV to perpetuate beliefs in casual transmission and, by extension, avoidance of those living with HIV.
- People recognize the role of limited knowledge in perpetuating stigma and are eager to acquire more detailed knowledge about HIV and AIDS.
- HIV is associated with socially “improper” sex. Consequently, people with HIV and AIDS are stigmatized for their perceived immoral behavior.
- Religious beliefs contribute to stigma by considering HIV as punishment from God for sexual sins.
- At the same time, religion and faith-based organizations offer comfort, care, and psychological and spiritual support to people with HIV and AIDS, as well as basic precepts for not stigmatizing people with HIV and AIDS.
- Many respondents express good intentions to not stigmatize, but stigma persists because people do not recognize words and actions as stigmatizing.

stigma. Attitudes and moral judgments, particularly about sex, shape how communities view people living with HIV. Finally, people are often unaware of their stigmatizing actions and of contradictions between what they say and what they do, and thus stigma persists.

### 5.1.1 Knowledge and fears

**5.1.1.1 Basic knowledge of HIV:** In all three countries, our data shows high levels of knowledge about the basics of HIV. Almost all of the Ethiopian respondents in the quantitative survey know at least one correct mode of transmission and prevention. The qualitative data from all three countries shows that a majority of respondents know that the main modes of transmission are through unprotected sex with a person with HIV or infected blood or needles. Many are also clearly aware that condoms are a key way to limit sexual transmission of HIV, and that reducing casual sex also reduces HIV risk. Similarly, people in all three countries are keenly aware of the fact of mother-to-child transmission.

**5.1.1.2 Lack of in-depth knowledge:** The data shows that an incomplete understanding of HIV and AIDS feeds fears about casual transmission. Many respondents do not understand that there is a difference between HIV and AIDS, how the disease progresses, and what the longevity of a person with HIV is. Fewer than one-third of the respondents in Ethiopia's quantitative survey know the difference between HIV and AIDS. Many respondents in all three countries believe that a person with HIV will die very quickly, if not immediately. As an urban Tanzanian man bluntly notes, "When they see that someone has HIV, they see him as already dead." Part of the reason for this belief is that, fearing stigma and discrimination, people do not disclose an HIV-positive status until it has progressed into AIDS and symptoms can no longer be hidden. In other words, families and communities typically are unaware that they know people with HIV until those people are in the last



*"This picture is about infected people who are sleeping on the floor, looking very lonely and eating on their own, while those that are not infected are joyful, playing and have vowed never to mix with the others for fear of infection."*

— Urban girl, aged 13, Zambia

stages of AIDS and, in fact, often near death.

Our data also shows that people with opportunistic infections (such as tuberculosis, chronic diarrhea, and herpes zoster) often are assumed to have HIV and, as a result, are also physically isolated and otherwise stigmatized. Furthermore, people often do not believe that opportunistic infections in those with HIV and AIDS are treatable and curable. While many do know that opportunistic infections such as TB are curable, others often equate TB with AIDS, consider TB symptoms to be those of AIDS, and thus consider opportunistic infections such as TB incurable. As urban Zambian male and female participants in a discussion succinctly say, "TB is AIDS."

For many individuals, correct, basic knowledge co-exists with incorrect knowledge. For instance, a male respondent from the rural site in Ethiopia says, "A healthy person might be infected if he sleeps with PLHA and if he uses an infected person's needle and plates and cups." While people know that HIV can be transmitted from mother to child, they often do not know how this occurs, nor that it does not occur in every case. Similarly, people know that HIV is transmitted through blood or sperm, but not the details of circumstances in which this transmission can and cannot happen.



**5.1.1.3 Fears of casual transmission:** In the three countries, people are trying to make sense of the prevalence and patterns of HIV. In high prevalence situations, people’s assumption that HIV can be casually transmitted is not surprising. The co-existence of incorrect with some correct knowledge about transmission fuels these beliefs. For example, people combine their knowledge of

the sexual transmission of HIV with the incorrect belief that a condom used by someone with HIV can transmit the infection through even casual contact:

*If the family suspected that one member has the HIV/AIDS, they think that the cows eat the grass in the compound and the grass could have been contaminated by the condom thrown in the field after use. So if children drink milk produced in such families, the children can be infected.* (Rural man, Ethiopia)

**Text Box 1: Community Recognition of the Role of Incomplete Knowledge in Perpetuating Stigma**

Respondents in all three countries recognize the role of limited knowledge—particularly knowledge of transmission—in allowing stigma and discrimination to persist:

*There are neighbors who visit the patient and there are those who don’t visit the patient. The neighbors who visit the patient know that AIDS is not transmitted through breath, but they know that it gets transmitted through using some materials [needle and razor]. On the other hand, neighbors who don’t visit the patient believe AIDS is transmitted through breathing or eating together.* (Rural man, Ethiopia)

As a result, a majority of respondents from all three countries, including PLHA themselves, strongly believe that promoting deeper understanding of HIV and AIDS will reduce people’s stigmatizing and discriminatory actions against people with HIV and AIDS:

*I think it is due to the lack of awareness and knowledge about HIV/AIDS. If the community has a deep awareness about HIV, they will take care of PLHA.* (Urban woman, Ethiopia)

Others, however, recognize that knowledge may be necessary but is not sufficient to reduce people’s fears and attitudes that lead to stigma and discrimination. As an urban Ethiopian woman notes, “Previously people even thought it can be transmitted with a cloth contact. At present, even though people know its transmission, they still have a fear.” Discussions in rural Tanzania yielded similar themes:

*Because this is a horrible disease, his or her friends know that they won’t become infected with HIV if they eat with him...but people will be scared of him/her all the same.* (Participant in an FGD of rural women, Tanzania)

Data from all three countries also shows that people recognize that their knowledge of HIV and AIDS is limited, and that they are eager to get more information.

Such fears of casual transmission result in immediate stigma and discrimination, as people fear not only physical contact with people who have HIV and AIDS, but fear contact with anything at all connected to PLHA. Cultural perceptions of disease can further add to these fears. These include beliefs in witchcraft as a cause of HIV, in rural Tanzania and Zambia; traditional beliefs (particularly in Zambia) about afflictions that people may suffer if they have sex with prohibited partners or come into contact with “polluted” people; and perceptions in all three countries of the hygiene and disgust associated with bodily fluids, such that blood, semen, saliva, sputum and feces are all considered similarly contagious when it comes to HIV infection.

**5.1.1.4 Fear of death:** Our data shows that there is a powerful fear of what is known to be a painful, certain death from AIDS. Respondents from Ethiopia and Zambia refer to HIV as a “killer disease.” As a rural Muslim religious leader from Ethiopia says:

*All diseases come from Allah. This one, however, is serious and has no medicine, [and so] we are frightened. It [AIDS] kills you by causing a lot of suffering.* (Rural man, Ethiopia)

Given this fear, people interpret the limited information to the best of their ability to make sense of their environment and to figure out how best to protect themselves. Therefore, minimizing contact with an infected person often becomes a protective measure that people take:

*At the market if they find the fellow marketer has HIV/AIDS, they start isolating themselves from that person...if it is the customer who is sick... even when this person comes to buy, they fear [they] can contract the disease, so they start hiding when they see this person.*  
(Participant in an FGD of rural men, Zambia)

The stigmatizing attitudes and behavior that arise from these fears are coping mechanisms, rather than an expression of power or control by dominant groups over other groups. Respondents recognize fear of HIV and AIDS as a cause for stigma and feel that stigma can be reduced if a cure is found, as voiced by this respondent:

*How can we reduce this stigma? It can only be reduced by finding a cure for HIV/AIDS. The stigma for HIV/AIDS comes about because it is fatal... whoever gets AIDS knows they are going to die and everyone around them declares them dead....The difference between AIDS and other diseases is that other diseases are curable. HIV/AIDS is not curable and that is how stigma comes in, but if cure can be found, stigma will go.* (Rural man, Zambia)

### 5.1.2 Sex, morality, shame and blame

In all three countries, much of the harshest stigmatizing language and discriminatory behavior centers on the sexual transmission of HIV. The very fact that HIV can be sexually transmitted bestows to it a separate status from other conditions. When asked why HIV is not considered a “normal disease,” an urban woman in Ethiopia replies, “This is because it is transmitted through sexual contact.”

Another Ethiopian respondent explains how he believes that HIV is different from fatal diseases like cancer:

*The other disgusting thing of this disease is that it is related with sexual intercourse....If someone gets sick [from] cancer, no one would isolate him. It is not considered as stigma.*  
(Urban man, Ethiopia)

**5.1.2.1 Norms about sexuality:** The data consistently and strongly shows that people believe that those with HIV get it through sexual activity that is not socially sanctioned or goes against religious teachings. Respondents in all three countries report that having HIV is a result of “deviant behavior,” and people with HIV and AIDS are regarded as adulterers, prostitutes, and generally immoral or shameful:

*The society perceives that someone gets HIV through prostitution. So when they see you they say, ‘Eehh look, she has got HIV, it is because she was a prostitute.’ They don’t know that anyone can get this through any other method.... In our society, prostitution is a very shameful word.* (Rural woman, Tanzania)

Where HIV is not considered to be a problem or threat, it is because people believe that there is no



“bad” behavior. “HIV/AIDS is not that [wide]spread in our community. The reason is most people are not prostitutes,” says an urban Ethiopian woman. A traditional healer in rural Zambia voices a similar sentiment, saying that “People think AIDS comes through immorality because a person misbehaved. If you behave, you cannot get it.” Rural men in Tanzania echo this theme: “I do not see HIV/AIDS to be a problem here because the children of today still live the old fashioned way, like in the past.”

Because people know that HIV is transmitted predominately through sexual contact, they distance themselves from those whom they believe engaged in behaviors they disapprove of:

*Families and relatives isolate their son who has AIDS because they think that he is promiscuous and he got infected while having sex with different people, and they assume that he doesn't respect their instruction and order. Because they feel this way, they kick him out of their house and isolate him. Due to this, he may die.*  
(Participant in an FGD of urban men and women, Ethiopia)

*“People at church, while others are late. People are praying in the church building, which is just finished being constructed. The woman who conducted prayers is teaching people not to mistreat orphans but to care for them. She even offers to pray for them”*  
—Urban girl, aged 11, Zambia

**5.1.2.2 Shame and blame:** The HIV-related stigma that is associated with breaking sexual

norms is heightened by the fact that people with HIV and AIDS are deemed responsible for their “deviant” sexual behavior. As an urban Tanzanian man puts it, “It’s disgusting to take care of an AIDS patient because it’s transmitted through sex, because he or she could avoid it.” An Ethiopian rural woman echoes this theme even more strongly: “Let God who created them cure them. I do not know who should take care of them. It was their own responsibility to take care of themselves.”

This attitude of blame justifies stigmatizing such an “irresponsible” person. Male participants in a discussion in urban Zambia feel that if a woman with HIV or AIDS is treated badly, it is not wrong “because she was sleeping around and that is where she got the virus so if anything, she deserves to be treated badly.” People also feel that HIV is a just reward for seeking illicit pleasures:

*Having looked upon how much he had enjoyed [sex], they say it is now time for pain. He just has to feel it, that there is no sweet without sweat. He was feeling sweet all the time; let him sweat for it.* (Participant in an FGD of urban men and women, Zambia)

**5.1.2.3 Sex and sin:** The interplay of sex with concepts of sin further contributes to sex-associated HIV-stigma. Echoing a broadly prevalent theme, an urban Ethiopian woman says, “They relate HIV with evil. They say it came from God.” An urban Tanzanian man notes, “So they say if you got it then you are like a Satan.” In Zambia, an urban man says, “[We] consider the sick to be more sinners than Satan.” This link among sex, religion, and stigma emerges particularly strongly in Ethiopia and Zambia, where data paints a picture of a strong belief that HIV is a punishment from God for sexual sins committed by humanity at large, and individuals in particular. Those who get HIV are supposed to have sinned, while following strict religious strictures is believed to ward off the syndrome:



*This disease is the result of our sin and our distance from religion. If we didn't commit sin, this thing would have never come. Thus God will be merciful for us if we get closer to our religion. If we do good things and obey God's law, there will be no disease that has no cure.* (Urban woman, Ethiopia)

People also believe that people with HIV and AIDS do not go to heaven because they have sinned, as these urban men and women in Zambia note: *"When a person dies of AIDS, that person doesn't go to heaven because that AIDS came for the sinners."* These perceptions of equating socially "improper" sex with religious or moral sin also contribute to stigma and

## **Text Box 2: Positive Role of Religion and Faith-Based Organizations**

While religion may play a role in perpetuating stigma, there is also evidence that religion and religious organizations provide valuable psychological support and comfort to people with HIV and their families and encourage non-stigmatizing behavior. Some religious leaders declare their support of people with HIV and AIDS, as illustrated by this quote from an Ethiopian priest:

*I will give him care. I will not be frightened. It is through relationship [sex] that the disease gets transmitted, not through eating and chatting with the patient. It is sexual intercourse that causes transmission. It is possible razor, needles can transmit. It is God who brought us this. I cannot throw away my relative.* (Rural man, Ethiopia)

Further, respondents in all three countries cite religion as a reason for not stigmatizing against PLHA. Even when people with HIV and AIDS are believed to have sinned, caring for them is seen as the moral response, while rejection is not. Those who are compassionate towards people with HIV and AIDS and provide them care are respected for being true to their faith, while those who stigmatize are frowned upon for not showing appropriate concern for fellow beings:

*They have abandoned her, showing us that there is no love just because she is sick, promiscuous and never listened to the advice of the neighbors including the family. We need not do that as Christians, what if it was us? We need to help and love because it is not good to treat others badly.* (Participant in an FGD of urban women, Zambia)

Similarly, people believe that it is up to God—and not humans—to decide whether and how judgment is passed, and that people's role is one of providing support:

*Provide him with all the services and when God decides to take him let Him do it, you can't punish him, you are not God.* (Participant in an FGD of rural women, Tanzania)

People who have HIV themselves turn to religion as a way of explaining why they have been "chosen" to suffer with HIV. As a woman with HIV in Ethiopia puts it, *"God gave me this thing and has reason for this."* Furthermore, those with HIV, and their families, find comfort in religion:

*My mother was upset. She tried to comfort me by saying that 'God will know and you will be cured by the holy water.' Then, I took holy water and I had hope on it. While I was taking holy water in the church, I listened to God's word.* (Urban woman, Ethiopia)

Religion also helps people caring for those with HIV or AIDS to deal with the fear around HIV and contracting HIV. As this urban Zambian woman taking care of person with HIV says when asked what her fears were in providing this care, *"I put everything in prayers... God is in charge of... me."*

Our study suggests that religion and religious organizations can play a role in fighting stigma by building on people's positive intentions as "good" practitioners of their religion, and by providing PLHA the psychological and emotional comfort that may be denied to them elsewhere. Religious organizations' role in comforting the soul, as perceived by PLHA, can also help to decrease internalized stigma by reducing the guilt that people with HIV and AIDS may feel.

discrimination within religious organizations themselves:

*Even at church it is the same thing. Most of them are condemning them, saying 'This one is not a Christian, and that is why he or she has this disease,' so they are rejected. (Rural man, Zambia)*

Religious leaders who acquire HIV not only lose credibility and status because the disease implies they have sinned, but are more heavily stigmatized than others because their position requires that they uphold a higher “moral” standard. As a traditional healer notes:

*The pastor [who has HIV] will be told to step down, he should not hold the Bible. The disease of HIV/AIDS is shameful to the congregation, and the pastor should not have this disease. (Participant in an FGD of urban men and women, Zambia)*

Unlike stigma that results from limited knowledge or fear, the stigma that arises due to perceived immoral behavior is of the classic type outlined by Goffman and by Link and Phelan, a mechanism used by the “normals” to keep the “deviants” at arm’s length. The data shows that this is achieved by making the stigmatized feel guilty, ashamed of themselves, sinners in the eyes of God and worthless to their families and communities.

### 5.1.3 Limited recognition of stigma

Despite the deep-rooted causes of stigma and the extensive stigma and discrimination that occur as a consequence, the data also suggests that people often do not recognize when their words, actions, or beliefs are stigmatizing or discriminatory towards PLHA. Respondents talk on one hand about how important it is to not stigmatize or discriminate and that they would never do so, yet at the same time describe how people who get HIV are promiscuous or indulge in other “immoral”

behaviors, and deserve what they get. Further, even those with good intentions exhibit discriminatory behavior, as illustrated by this quote:

*Yes, I can take care of a person if I am told that he has HIV. And if I know that he has got it, I will never have a coffee with him... I will tell to his relatives that this thing is harmful and that they should hold him back from coming to my home. (Rural man, Ethiopia)*

This lack of recognition of one’s actions creates a gap between good intentions not to stigmatize or discriminate and actual stigmatizing and discriminatory attitudes, language, and actions, as this quote illustrates:

*I will not discriminate [against] him because he has the disease. I will console and be close to him... I would put his things, clothing and those utensils he uses separate. I will ask him what help he needs and buy him things he needs, but make sure that members of the family, including children, do not use things he uses. (Rural man, Ethiopia)*

Even when people are aware of their stigmatizing behavior, they may defend this simply as being self-protective:

*It is not really stigma but other way of lessening the HIV/AIDS and TB disease, by practicing preventing measures, so that other diseases like TB... don't infect you. Is there anyone who would like to eat with a person who is bleeding and that blood is dropping in the food? In that situation you can't accept to eat the same food because you don't want to be infected with disease. (Participant in an FGD of urban women, Zambia)*

As most of these testimonials illustrate, even when people harbor no ill will towards those with HIV or

### Text Box 3: Good Intentions to Not Stigmatize

In all three countries, a significant portion of respondents express the sentiment that people with HIV and AIDS should not be blamed, isolated or otherwise mistreated. As rural men in Tanzania point out, *“I think it will not be fair because there is no one who says, ‘I want to catch HIV.’”* Over three-quarters of respondents in Ethiopia’s quantitative survey feel that people with HIV deserve care, whether they are unmarried or married, men or women, children, community leaders or prostitutes. In some cases, the intention not to blame may arise from a sense of fatalism about how widespread HIV is and the knowledge that it can affect everyone:

*One cannot be blamed because this disease is just like malaria nowadays, it is everywhere and everyone is committing adultery. . . . We will not isolate this person if she or he comes back home because he didn’t want to settle. . . . the father may step out of the family just once and get the disease then bring it home to his wife. Later when they become sick, you may not be able to tell who infected the other in the first place. So we will just stay with them, waiting on who is going to be the first.*

(Participant in an FGD of rural women, Tanzania)

Respondents appear to recognize that stigmatizing and discriminating against people with HIV and AIDS only serves to make their lives worse, and thus is not acceptable:

*Respondent: In the village, looking at this picture, these people are coming from the field. . . they have left the patient alone in the house and they are rushing home to go and prepare food for him. This patient at home disturbed them, they don’t finish the work at the fields properly. The patient also complains to them to say they take a long time to give him food. They will blame the patient all the time.*

*Interviewer: Is this behavior acceptable?*

*Respondent: No.*

*Interviewer: How does the behavior affect the person living with HIV/AIDS?*

*Respondent: The patient will feel neglected by other family members.* (Participant in an FGD of rural women, Zambia)

Respondents also feel that families and communities should comfort and care for those infected with HIV, as voiced by this rural Ethiopian woman: *“We should not be far away from the infected person. We should rather solace him.”* Some go a step farther to say that caring for those with HIV is the best way to address the epidemic:

*Interviewer: What could be the best way to solve such problem?*

*Respondent: We should learn to accept this disease, to love people living with HIV/AIDS. Accepting them as our family members, coming close to them and always trying to help them.* (Participant in an FGD of rural women, Zambia)

Overall, good intentions co-exist with stigmatizing behavior in all three countries. Building on these intentions can provide an effective entry point for addressing stigma in the household and the community.

AIDS, their incomplete understanding of the disease results in actions that effectively stigmatize them nonetheless. In considering such stigmatizing attitudes and actions to be “normal,” they inadvertently are perpetuating stigma and discrimination.

## 5.2 The context of stigma

Consistent with the theoretical literature reviewed earlier, our data shows that individuals’ experience of stigma is intertwined with the context of their

lives. In particular, socio-economic status, age and gender influence the stigma and discrimination experienced by people with HIV or AIDS, and their ability to cope with this stigma.

### 5.2.1 Socio-economic status

**5.2.1.1 Perceived risk of HIV infection:** In all study sites, rich and poor people experience HIV stigma differently. Respondents<sup>5</sup> believe that the wealthy face HIV risk because their wealth allows them to live a lifestyle that includes having extra-marital

<sup>5</sup> Because this study was not conducted in affluent communities, the respondents are predominantly poor. It is their perspectives on poverty and wealth that are represented in this section.

### Summary of findings about the context of stigma

- The poor are blamed less for their infection than the rich because people believe that the poor are compelled to engage in risky behaviors because of their poverty.
- At the same time, the poor face greater stigma than the rich because they have fewer resources to hide an HIV-positive status and pay for non-stigmatizing care.
- Young people are considered most at risk and are most highly stigmatized because of the perception that youth engage in careless, highly risky sexual and other behaviors, and do not heed tradition or the advice of parents and elders.
- Both women and men are stigmatized for breaking sexual norms for their gender. However, gender-based power imbalances make it easier for women to be blamed.
- Women infected by their unfaithful husbands and women forced into risky behavior because of poverty are sometimes viewed more sympathetically.
- The consequences of HIV infection, stigma, disclosure, and the burden of care are more severe for women than for men.
- HIV stigma is often overlaid on other stigmas, creating multiple stigmas for certain groups such as young female sex workers.

partners, drinking, or paying for sex, and because their wealth attracts women and girls. As an urban Tanzanian man says, *“It’s easy for a rich man to get AIDS because he uses his money to corrupt every kind of woman he likes.”*

On the other hand, it is the shaky economic position of the poor that is believed to push them into risky situations. As articulated by a rural man in Ethiopia, *“A poor person would do anything to survive and is exposed to HIV risk.”* Respondents in all three countries feel this is especially true for poor women who are compelled by their poverty to have sex for money:

*A woman can see that her man at home has no money so she decides to take other alternatives to cover her needs, so she has other partners at the side. You see that these days... business can be tough, so she sells herself so that she gets some money. (Urban man, Tanzania)*

**5.2.1.2 Blame, sympathy and stigma:** Because rich and poor people are assumed to be infected with HIV for different reasons, rich people with HIV are often held responsible for getting HIV whereas poorer people with HIV are sometimes regarded sympathetically. The difference is that the rich presumably choose the “immoral” behavior that causes them to contract HIV, but it is believed the poor do not “choose” to become infected.

Wealthy men, in particular, face accusations that they intentionally spread HIV, as described by this urban Tanzanian man: *“There was this man who had a lot of money and was using it to spread the disease.”* In Tanzania and Zambia, it is believed that rich, older men specifically try to lure young women into sexual relationships.

However, the poor do not completely escape blame if they are HIV-positive. As noted in a discussion among rural Zambian women: *“The poor are isolated; they say it is his fault.”* While the rich may be blamed for their infection more often than the poor, poor individuals with HIV and AIDS experience greater stigma because they lack the means to hide their HIV status. The rich can afford to get care from outside the community, even abroad, ensuring that no one in the community will learn of an HIV-positive status. In contrast, poorer people are often forced to disclose their status in order to access services and benefits, making them more vulnerable to stigma:

*The [HIV status of the] rich will not be known because being treated by his own money can hide him. But the poor [must] tell his problem to people who live near him, his neighbors, the community and the government, in order to be supported.... The poor must tell openly in order to get... medical treatment. (Urban woman, Ethiopia)*

## 5.2.2 Youth

**5.2.2.1 Perceived risk of HIV infection:** In every country, young people are identified as being most at risk of HIV because youth are highly attracted to money, material goods, and sex. As a group of rural Tanzanian men say, *“I think this problem of HIV is in these youths. They are so much after money.”* Young people are also considered high-risk because of the perception that they engage in “bad” behaviors such as frequent and unprotected sex and drugs and alcohol use. As described by several Ethiopian respondents, young people are in the “fire age” where they cannot control their sexual desires. In all three countries, the perception even among the young is that these behaviors put them at risk because they consider themselves invincible, and because they are unmarried:

*I think this issue of HIV/AIDS for us people who are not yet married is somehow dangerous.... But the problem with our youths, if you tell them to abstain from sex, they say haa you, you cannot just force me. (Participant in an FGD of rural men, Tanzania)*

Youth also indulge in risky behaviors when they have few economic opportunities. Thus, poverty and age combine to increase HIV risk for youth who have little to do and few places to go to that cater to their needs:

*Young people...are unemployed. There is no recreational place, no library, which can occupy their mind or there is no recreational center where they read books and spend time. Due to this, they [entertain themselves] by chewing khat<sup>6</sup>, smoking cigarettes and taking drinks and drugs. These behaviors expose them to the disease. (Rural man, Ethiopia)*

**5.2.2.2 Blame:** While youth experience all forms of stigma, blame is strikingly prevalent. Largely because of the belief that youth lead a careless life



and are highly sexually active, young people in all three countries are not only believed to be at risk but are blamed for getting HIV through their promiscuous, immoral, and “improper” behavior:

*Then after a while you hear her [a young girl] complaining that she is sick. When people look into her behavior, all they see is alcohol and local dances to be her most important luxuries. (Urban man, Tanzania)*

Several respondents realize that young people have little information and support to protect themselves from HIV. Other respondents feel that the information exists but that youth choose not to change their ways, as illustrated by this quote from a peer educator in Zambia:

*Information people are getting is straightforward. There are a lot of programs on the radio and there are so many handouts. The problem is the youths who are stubborn. [We have] the message, but we are not doing what the message is saying. Condoms are there but how many are using them? Just a few. (Urban man, Zambia)*

<sup>6</sup>Khat is a leaf with psycho-stimulant properties.



Furthermore, youth are blamed for not heeding parents' advice and for scorning parents' and community traditions that many elders perceive as protective against "bad" behavior and subsequent illnesses like HIV. As described by an urban Tanzanian man, *"The big problem for youths is that they tend to ignore."*

Youth are also blamed for bringing HIV into the community. In some cases in urban Tanzania, young people, particularly men, who moved into a neighborhood were suspected of coming into the community to intentionally spread HIV. This perception is fuelled by the fact that young urban men are a naturally mobile population who often move into communities that know nothing about them. In Ethiopia, young people's "sinful" behavior is considered the reason for their community being "cursed" by God with HIV:

*The youth is blamed; the elderly men and women blame the youth for bringing the disease and making God angry and passing on them His verdict. The sexual behavior of the youth is taken as a cause of HIV/AIDS transmission.* (Rural man, Ethiopia)

## 5.2.3 Gender

**5.2.3.1 Perceived risk of HIV infection:** In all three countries most respondents think that women are physiologically at higher risk of infection than men. On the other hand, there are strong beliefs about men's versus women's risks of HIV based on the perceived extent of "wrong" or "immoral" sexual behavior that men and women engage in. These perceptions are influenced by underlying norms about women's and men's sexuality. When men are considered to be at higher risk than women, male and female respondents in all three countries attribute this risk to men's "natural" propensity for sex. Urban women in Zambia note that *"Men are naturally womanizers."*

Women are believed to have more controllable sexual urges and thus to be less at risk of HIV:

*I think men are the most exposed ones because women can control their sexual feeling and they even can wait if they decide not to marry earlier. But men can't control their sexual feeling.* (Participant in an FGD of urban women, Ethiopia)

*The way we are, men are very difficult to control, it's easy for the women to be faithful in their marriages.* (Participant in an FGD of rural men and women, Tanzania)

When women are considered at risk, it is because they are thought to be unable to protect themselves against unwanted sexual advances or rape. This perspective is particularly strong in Ethiopia:

*Women get infected more likely than men... a woman who is found walking on a street after 10 p.m. will be raped. Besides, she has no strength to escape from men.* (Urban man, Ethiopia)

Women's and men's social roles also play a part in perceptions of risk. Married women are perceived to be at greater risk because their husbands are unfaithful. As explained by a group of rural men and women in Tanzania: *"It is us women... because men go out fooling around while we stay at home."*

**5.2.3.2 Blame:** As with risk of infection, the reasons given for blaming men or women for being the ones to bring HIV infection into the partnership, home, or community are intricately tied to socially accepted norms regarding gender-specific roles, responsibilities, and sexuality. Both men and women who transgress these norms face blame.

When men are blamed—by women or by men—it is with an underlying assumption that the behavior is to be expected, in tune with social perceptions of men’s proclivity for multiple sexual partners:

*We men are to blame because we normally say that you don’t need to have the same kind of meat every day, meaning that despite your real girlfriend, you have other multiple girlfriends somewhere else.* (Participant in an FGD of urban men, Zambia)

The one exception is older men in relationships with very young women, which is considered to be unacceptable. There is widespread consensus in this regard, particularly in Zambia.

Those who blame men perceive women as the “innocent victims,” too immersed in their duties as wife and mother to have time for extra-marital sex:

*As to the community, the man is blamed more. In our community women are burdened with work, thus they do not go out as they want. Thus the man is the one who goes out for recreation mainly. Women also could bring the virus to her husband, but the man is the one who is blamed most.* (Urban woman, Ethiopia)

In some cases, the husband is also blamed for not having fulfilled his socially-expected role as provider:

*Women only spread HIV when the husband [is] not responsible, so she might be trying to look for money to help in the family or when the husband is a drunkard.* (Participant in an FGD of urban men and women, Zambia)

While men often are blamed for infecting married women, some respondents also blame single

women for bringing HIV infection into the community. The type of blame, and the extent of stigma attached to a woman believed to be the first infected, depends on the perceived source of infection. Women who are believed to engage in socially “improper” sex because of economic necessity or to provide for their children are usually not blamed for HIV:

*The way I see it is that sometimes these unmarried women may have children... they may be forced to do anything so they can feed their children. So they may be ready to give or do something they never intended to... they will be asked for sex if they are to be given some money.* (Participant in an FGD of rural men, Tanzania)

The worst blame and other forms of stigma are reserved for those women thought to be responsible for HIV through “improper” or immoral sexual behavior. For instance, women who dress in ways considered immodest, particularly urban, young, and mobile women, are highly disapproved of, as illustrated by this quote from an urban Ethiopian woman: “I don’t feel sorry for the city girls even if they all die of this disease since they go here and there.” Such “bad” women are considered shameless, out to tempt men who are thus considered the victims:

*A prostitute, just from the way she is dressed, you can tell what she is up to... they dress up for attraction, they try by all means to tackle men’s weaknesses.* (Participant in an FGD of urban men and women, Zambia)

Gender-based power relationships also play a more direct role in the blame women face. As men and women in a discussion in urban Zambia note, “The reason why the man blames the woman is because he is the one who has power over the woman.” Respondents also say that even if it is a

man who brings the infection to the couple, this power allows him to shift the blame and stigma to his female partner:

*She will be blamed, saying you have given it to your husband but meanwhile it is the husband who has given it to her. I might transmit the disease to my wife then tell my wife to go for an AIDS check up. If she is found positive I blame it on her and tell the whole community that she has infected me.*

(Participant in an FGD of rural men, Zambia)

Our data strongly suggests, in other words, that though both men and women who do not conform to sexual and gender norms are blamed for HIV, the structure of gender-based power means that women are more easily blamed and that women's transgressions tend to be regarded more severely than are men's. The only exception is women who are believed to have become infected due to extenuating circumstances, such as poverty.

#### 5.2.4 Multiple stigmas

One underlying contextual theme in all three countries is that of HIV stigma being overlaid upon other pre-existing stigmas. A clear example, as illustrated by quotes earlier in this report, is the multiple stigmas faced by sex workers, who are stigmatized for being sex workers, women and HIV-positive all at the same time. In fact, much of the harshest language is used in reference to sex workers.

The particularly severe HIV stigma faced by the young, poor and women is also partly due to the existence of multiple, layered stigmas. Regardless of HIV, the poor are considered to be of a lower social status and are often marginalized as a consequence. Women also are marginalized and discriminated against relative to men in the family and society. Finally, the young often are regarded with less respect and greater impatience because

of their lack of experience in the world and perceived lack of obedience to elders. When any of these characteristics combine, therefore, they can result in even greater marginalization and a lower social status—for instance, young, poor women are often at the bottom of the familial and social hierarchy.

These already-marginalized groups face additional stigma when HIV is involved, though not always in expected ways. Gender and poverty intersect, such that poor women are not blamed for HIV infection, while rich men are. Age and gender also intersect such that younger women are more stigmatized and blamed for HIV than older women, because of beliefs that young women—but not old women—lead promiscuous, careless, materialistic lives that result in HIV:

*An older woman cannot be infected... younger women are the ones who are at risk of infection. Younger women are looking for marriage, money etc.... Older women... don't involve themselves in any relationship.*

(Participant in an FGD of urban men and women, Zambia)

Another example of multiple stigmas is HIV stigma in conjunction with the stigma associated with real or perceived infertility. This dual stigma is most often faced by young, married women with HIV, as interviews in Tanzania show. On the one hand, it is unacceptable for young, married women to either not have children (in which case they are assumed to be infertile and stigmatized for it) or to stop childbearing before having the socially-expected number of children (in which case they may be stigmatized for breaking social and gender norms). On the other hand, the community frowns upon women with HIV having children. Thus these young women face multiple, simultaneous stigmas.<sup>7</sup>

<sup>7</sup> More detail on the situation of HIV-positive, young women in Tanzania can be found in the Tanzania country report.

Our findings on the causes and context of stigma clearly show that whether or not, and the extent to which, people with HIV and AIDS are stigmatized and discriminated against depends on “who” they are (for instance, whether they are men, women, sex workers, youth, rich, poor), “where” they are (for instance, at home, in the health center, in the church), and “why” they are infected (whether they are assumed to be responsible for their infection). The next section elaborates on the “what”—in other words, what are the manifestations and experiences of this deep-rooted stigma in these three study sites?

### 5.3 Experiences of stigma

Experiences of stigma and discrimination are strikingly similar across the countries. These manifestations of stigma appear in multiple ways and vary from the overt and blatant to the more covert and subtle. Whether overt or not, the experiences of stigma and discrimination take three broad forms: stigma and discrimination against people living with HIV and AIDS; internalized stigma of people with HIV and AIDS; and stigma and discrimination against those related to or associated with PLHA (secondary stigma), such as children, family, caregivers and health care workers.

#### 5.3.1 Stigma towards people living with HIV and AIDS

The data highlights that stigma towards people infected by HIV and AIDS is manifested in differential treatment, gossip, loss of identity or role and loss of resources and livelihoods.

**5.3.1.1 Differential treatment:** The most common forms of differential treatment are physical or social exclusion from the family and community, and changes in care and support by the family, community and health system.

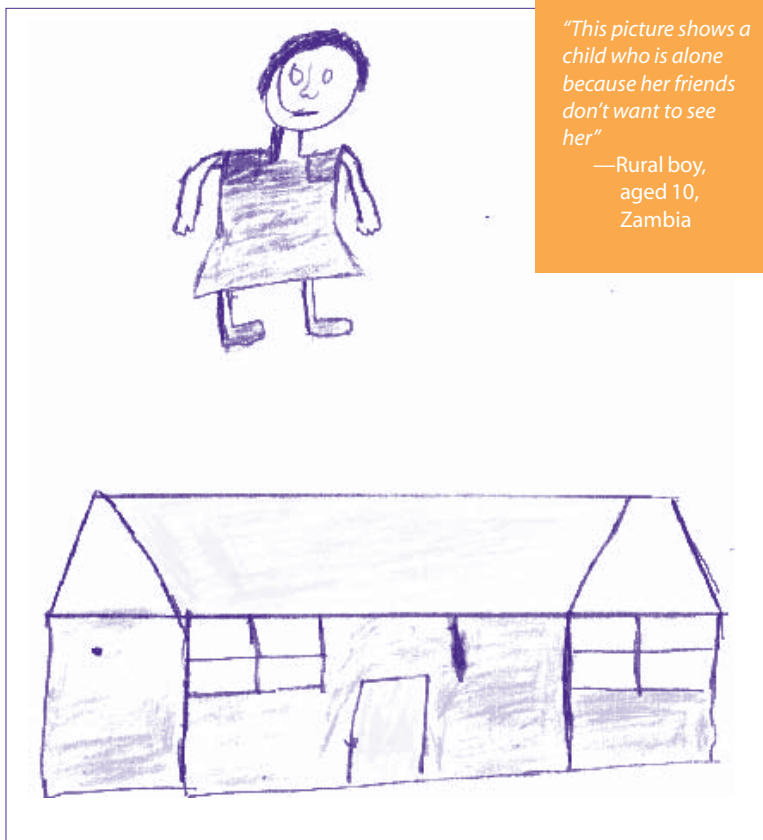
#### Summary of findings on experiences of stigma

- People living with HIV and AIDS experience physical and social isolation (such as separation of linens and decreased social interaction); gossip, rumor, name-calling and voyeurism; loss of rights, status and decision-making power in the household and community; and loss of access to resources, such as housing and employment.
- People living with HIV and AIDS internalize the negative views of them, leading to feelings of guilt, self-blame, inferiority, self-isolation, despair, loss of hope and abandonment of life aspirations.
- Those associated with people who have HIV and AIDS experience secondary stigma in many of the same forms as primary stigma. It is felt most strongly by family members, children, caregivers and friends.
- While stigma is widespread, PLHA also often find empathy, understanding, and support from family members, friends and the community.

Physical exclusion occurs across all three countries, through isolation of the person with HIV or AIDS, separating sleeping quarters, marking and separating eating utensils, separating clothing and bed linens and no longer allowing the person to eat meals with the family:

*When they found out that he was HIV-positive, they started giving him his own spoon, water container, plate, cup, and everything by himself. (Urban woman, Tanzania)*

*Many will isolate the person by taking him or her in another room to be alone. They don't want to mix with others in the main house. (Rural man, Zambia)*



*“This picture shows a child who is alone because her friends don’t want to see her”*  
 —Rural boy, aged 10, Zambia

Across all three countries, respondents also mention that families hide HIV-positive relatives so that others will not see that a family member has HIV:

*For example, if a patient gets sick seriously [suspected AIDS]... they might hide the patient to some other place and finally we hear as the person passed away. Thus, people isolate PLHA. Family would rather say ‘he or she is now better’ or they might say ‘he has slept’ and so on. (Urban woman, Ethiopia)*

Respondents recognize, however, that only families with resources could successfully manage to hide their infected family members and that poorer households would eventually have to ask for outside assistance.

A more subtle form of physical exclusion described by women in Ethiopia is no longer being allowed to participate in daily household work, particularly

in food preparation. Household members explain that this change in daily routine is needed to give the person with HIV rest and to save up his or her strength.

Social exclusion usually manifests itself as the reduction of daily social interaction with family and neighbors, exclusion from family and community events, and shunning or turning away by the public. Respondents describe a distancing, where friends and neighbors no longer visit, or visit less and less frequently. They also describe a decrease in common daily interactions between households like borrowing small food items or household implements. As explained by urban men and women in Zambia, *“Neighbors... would stop sharing the use of things like buckets, stools, and getting cooked stuff from the victim’s household.”* People with HIV and AIDS also are excluded from family and community special events and gatherings. For instance, an urban Tanzanian man observes that they may stop receiving invitations to participate in family or communal governing meetings, such as family councils, and social events and gatherings, such as weddings.

Social exclusion by the broader public occurs in public venues like stores, social gathering places, and public transport. As a woman in rural Zambia explains, *“No one would sit next to you [on the bus]... maybe you cough and everybody [has] their eyes on you.”* A Zambian male traditional healer confirms that even in church, *“Others will shun away not even sit together on the same bench.”* This type of public rejection is described most often in Zambia, particularly in local bars:

*In the bar... if someone has HIV/AIDS, people wouldn’t want to drink with him, sometimes others would chase him, saying ‘get out of here, please leave us, you are going to infect us.’ (Participant in an FGD of rural men and women, Zambia)*

**5.3.1.2 Gossip, voyeurism and taunting:** Talking ill about a person with HIV and AIDS is described across all three countries as one of the most common and feared manifestations of stigma. People recognize the use of language as a stigmatizing tool and its negative power. As explained by a community leader in urban Zambia, “It is not sometimes the disease that kills these patients, it is the bad words and remarks from people.” Gossip has harsher consequences for women who generally rely more heavily than men on social networks, particularly when their access to and control of economic resources is limited, as in our study areas.

People with HIV and AIDS and others in communities describe how family, friends, co-workers and neighbors gossip, speculate and spread rumors about whether a person is suspected to have HIV, how that person is assumed to have contracted HIV, that they deserve HIV and

how they are now “useless” and going to die soon. This leads to insults about the person with HIV or AIDS, talking and whispering behind his or her back, laughing and pointing fingers as he or she passes by, teasing, mocking, taunting and scolding:

*In this community people repeatedly gossiped about me [when I was sick], saying, ‘It is cobra, it is AIDS’.... I faced it myself, I am afraid of AIDS very much. While I was sick, my neighbors came and visited me, but from behind they were rumoring [gossiping] about me. (Rural woman, Ethiopia)*

People with HIV and AIDS are also taunted and scolded for not listening to the advice of elders:

*They usually blame the children for bringing trouble in the house. They say, we used to tell you, but you didn’t want to listen. (Participant in an FGD of rural men and women, Zambia)*

#### **Text Box 4: Words that Hurt**

In each country, specific derogatory words and phrases have emerged to describe people living with HIV or AIDS or the syndrome itself. The use of these words is a powerful means to stigmatize. Terms with negative connotations are part of daily conversation and are used in rumors, gossip and even the media. Often, however, speakers are not aware that they are stigmatizing with their words or of the damaging impact of what they are saying. Nonetheless, the phrases that highlight deviant behavior in connection to HIV or euphemisms for death and physical appearance only reinforce perceptions that people with HIV are unproductive, useless, responsible for their infection and a burden to those around them. Common terms to describe PLHA or the syndrome include the following:

##### **In Ethiopia:**

- “yeminkesakes atent”—moving skeleton
- “mote bekeda”—almost dead although still living
- “menfese mute”—ghost

##### **In Tanzania:**

- “maiti inayotembea”—walking corpse
- “marehemu mtarajiwa”—a dead person to be
- “utakufa kilo 2”—you will die weighing 2 kilos

##### **In Zambia:**

- “makizi yaku mochari”—keys to the mortuary
- “kaliyondeyonde”—skeleton
- “kalaye noko”—say goodbye to your mother



Gossip often includes a degree of voyeurism. The data describes how people speculate on how a person with HIV or AIDS is progressing. They visit people with HIV or those sick with AIDS not out of genuine concern or to offer help, but to see how the person is doing in order to report back to others in the community on what symptoms the person has, and how sick he or she is:

*[People go] to see someone [with AIDS] for the purpose of making an amazement of him.... Others are going there to make a mockery. They are just coming to glare at you. (Urban woman, Tanzania)*

**5.3.1.3 Loss of identity and role:** People living with HIV and AIDS are viewed by the community as having no future or hope and are no longer considered productive members of society:

*At school...if you know some of the pupils have got HIV, that person is going to be isolated by his friends... they will be looking at him as somebody who is nobody, he is going nowhere...he is useless or whatever he is going to do is going to fail. So he is considered a failure in life. (Participant in an FGD of rural men, Zambia)*

In addition, once their positive HIV status is known, PLHA are sometimes treated as if they suddenly have lost the ability to function, both physically and mentally. They lose power, respect, and the right to make decisions around their own life, particularly with regard to their own care (often reflected in well-meaning advice, for example admonishments like “don’t drink, don’t smoke, don’t have children”). They may not be allowed to work or choose what kind of work they will do, and sometimes even whether they can have visitors.

At the same time, people with HIV appear to acquire (in the eyes of the community) a new role and responsibility towards the community: to disclose their status publicly and “teach” others how they “got it” so that people can learn from their “mistakes.” People with HIV and AIDS who do not fulfill this responsibility to “teach” are considered irresponsible and selfish. Over three-quarters of respondents in the Ethiopian quantitative survey think that PLHA should disclose their status so that they can educate the community about HIV. This theme is echoed in the other countries as well:

*If she is really a concerned citizen, she can disclose her status and help other people to know more about HIV/AIDS...she can even start an NGO [so] people [can] go there and ask questions, and [she can] share other things about AIDS. (Participant in an FGD of rural women, Zambia)*

**5.3.1.4 Loss of access to resources and livelihoods:** One resource people commonly report being denied is housing. Particularly in Ethiopia, people report being evicted by landlords who suspected them of having HIV, regardless of whether or not they were infected. Fear of eviction, in turn, is enough to deter disclosing one’s HIV status beyond a few trusted individuals:

*I was searching for a house [to rent] far from the village, but it was difficult to find one because the rumor [that I had HIV] has also spread widely. When house owners heard the rumor, they [would] cancel the deal and tell me that they do not want me. I went through long up and downs to get the present house I am living in and the owners still do not know that I am HIV-positive.* (Urban woman, Ethiopia)

The data across the three countries is rife with evidence that stigma and discrimination diminish livelihood options. Respondents cite loss of employment, business, customers and assignments if people know that they are HIV-positive.

Loss of employment can occur after an employer learns of an employee's positive status (which can happen as a result of visible signs and symptoms or repeated need of sick leave). Employment can also be denied if an application requires an HIV test with a negative result.

Loss of livelihood is described most commonly with respect to vendors who sell food or produce. In the Ethiopia quantitative survey, almost two-thirds (61 percent) of the respondents say they would not buy food from a vendor with HIV or AIDS. In all three countries, there are numerous reports of customers shunning vendors they suspect to be HIV-positive, as this woman with HIV describes:

*I cook buns and fry fish and groundnuts for sale, [but] nobody will buy my fish if I am infected with HIV. They will say, 'What if she bent and the sweat dropped onto the frying pan?'* (Urban woman, Tanzania)

As the quotes throughout this section illustrate, PLHA experience stigma and discrimination not only because they are perceived to be worthless and facing imminent death, but also due to

incorrect knowledge and beliefs regarding casual transmission. Thus, because of limited knowledge, fears surrounding HIV, and social norms about the nature of sexual transmission, people with HIV and AIDS face stigma and discrimination in multiple arenas of their lives: in the home, in the community, in the school or workplace, and in the health care setting.

### 5.3.2 Internal stigma

In all three countries, as a result of facing constant pressures to deal with HIV and AIDS along with overt and subtle stigma and discrimination, people with HIV and AIDS often internalize stigma. This is a complex process that involves internalizing the devaluation from people around them.

Internalized stigma is further complicated by the despondency and feeling of utter helplessness that comes with a condition that is believed to be a sentence of death without any possibility of reprieve. Three broad themes emerged from the data that show how PLHA internalize stigma: people with HIV internalize guilt and blame for being HIV-positive and accept their inferior status in society; they are psychologically affected by stigma and become despondent and lose hope; and they tend to isolate or separate themselves and even give up on previous life aspirations.

#### 5.3.2.1 Internalized guilt and self-deprecation:

Our data shows that PLHA often internalize and accept the negative views of themselves held by others. Internal stigma is recognized both by people with HIV and AIDS and the community as being present and damaging, with a variety of manifestations. People with HIV and AIDS express the belief that they are of a "lesser status" than those without HIV:

*Because I have the virus in my blood, I came to understand that my father does not see me equally like his other daughters. I became really sad. I felt inferiority and I realized that I am below any person.* (Urban woman, Ethiopia)



Feelings of guilt and self-blame for having HIV are strong among PLHA in the three countries:

*Almost 75 percent of PLHA feel guilty because they have HIV. They couldn't live longer with HIV because they assume that they infect their wife and child and cause economical problem to their family. Thus, the majority of PLHA feels guilty, sinner and criminal for having HIV. And*

*it is difficult for most of them to avoid such kind of thought. (Urban man, Ethiopia)*

*[PLHA] will say, 'Why my neighbors don't want to visit me? But I am sick,' and he will blame herself or himself and questioning on misbehaving, immediately becoming disturbed. (Participant in an FGD of rural men, Zambia)*

### **Text Box 5: Positive Experiences While Living with HIV and AIDS**

While stigma is pervasive, our data provides instances of people with HIV and AIDS surmounting the stigma they face to maintain positive attitudes and an eagerness to be leaders in society. There are also examples given by PLHA of the support and encouragement they receive from family and others which enable them to shoulder the burden of HIV and AIDS.

In several interviews with people with HIV and AIDS, respondents show a determination to face HIV in constructive ways despite stigma and discrimination. Data from the one-month follow up in the VCT study in Tanzania shows that some clients, despite their shock at their own status, are already thinking about helping and encouraging others to get tested:

*Now is [the time] to learn how to care for yourself and to tell others not to believe because they are fat with good health [that they don't need to be tested]... the good thing is advise each other, and try to educate each other... the only sure way is to test. (Urban man, Tanzania)*

The diaries kept by PLHA in Ethiopia provide additional examples of people who have disclosed their status publicly, despite the lack of understanding and subsequent stigma from their own families. Some welcome a chance to publicly disclose and share their experiences in an effort to prevent further spread of the disease, even though they are aware of the discrimination they could face as a result:

*If I get the chance to teach through media, I will give my address through television and radio. However, they will point fingers at me since there is a lack of knowledge and even if they point fingers at me what I think is to rescue them, at least one in a hundred. I am living with the virus; however I don't have the intention to infect others. Rather, I want others not to be exposed as to what has happened to me. I want to share my experience with the youth. This is all I have. (Urban man, Ethiopia)*

While many households stigmatize and discriminate, people with HIV and AIDS interviewed for this study also describe supportive families and communities that enable PLHA to fight stigma elsewhere:

*I am living a happy life.... Even if I have a problem in my day-to-day life, I will compensate the problem with the community's positive treatment... the love and the treatment that is given from the community helps me to live in a free way and make me happy. (Urban man, Ethiopia)*

Similarly, there are cases of others affected by HIV who face stigma because family members died of AIDS but who still intend to use their experiences to help those they can. As this urban Zambian peer educator, whose brother died of AIDS, says:

*I feel so bad because even as the people see me they'll be thinking of HIV/AIDS and it will be the talk of the community. Mostly the fear is getting infected because maybe you've got a cut and that person who is sick has a wound.... What I can do about the fears is just to teach the people, educate them, use simple language so that they are well informed. (Urban man, Zambia)*

While the examples above may be exceptions to the general picture of widespread stigma and internalized stigma, these positive experiences illustrate the important role that people with HIV and AIDS themselves play in fighting stigma.

**5.3.2.2 Despondency, despair and loss of hope:**

The data shows that because HIV is a chronic illness and because those with HIV internalize stigmatizing messages about themselves, people with HIV and AIDS may feel an immense sense of anguish and hopelessness. The resulting psychological trauma PLHA experience includes a deep sense of despair and despondency. People with HIV often feel that they have nothing to offer to society and that they no longer have a purpose in life. As one woman in urban Ethiopia describes, “I really felt depressed. I said to myself, ‘I cannot have any vision about the future so long as I have the virus in my blood.’” The combination of shame, suffering, and despair leads PLHA to feel that they are less deserving of life, and to thoughts of suicide. As these women from rural Zambia explain, “People keep away from him [PLHA]. A person feels abandoned. Thinks of suicide or stay away in the bush... this person feels bad.”

**5.3.2.3 Self-isolation:** Another form of internal stigma found in our data is self-isolation, or voluntarily withdrawal from social interactions and community life due to a poor sense of self-worth:

*All my brothers and sisters took the test and were free from the virus. I felt that I was a condemned person from the family for living with the virus.... I was really sad because I felt I was different from the family.... I started isolating myself and decided to live in a different house with people who have the same problem.* (Urban woman, Ethiopia)

**5.3.2.4 Abandoning life aspirations:** Some people with HIV and AIDS describe how their lesser sense of self-worth and loss of hope lead them to abandon their life plans and dreams. For example, they might hesitate to pursue new employment or promotions at current jobs, continued education or higher levels of vocational training, or health care; they might give up on scholarships or travel; or they might abandon

aspirations for marriage or having children. Examples of people with HIV saying they were giving up on plans for education were particularly common in Ethiopia:

*I was hoping to continue my education till I was told that I am HIV-positive. And I couldn't succeed even though I tried after that. I was anticipating myself for great success but I failed.* (Urban man, Ethiopia)

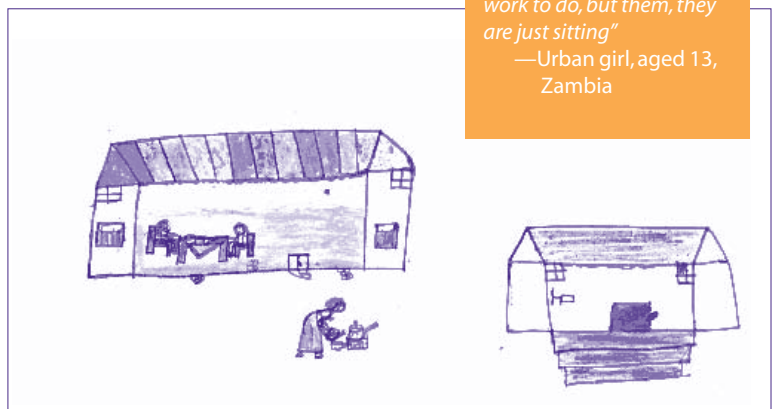
**5.3.3 Secondary stigma**

Secondary stigma manifests itself in many of the same forms as primary stigma, but in particular through social exclusion and gossip about the behavior and HIV status of those associated with PLHA. While it is faced or experienced by all people who are associated with people with HIV or AIDS—family members, children, caregivers and even friends—those most affected are children and other family members. Families, in particular, are stigmatized if certain family members have HIV or AIDS. Parents and their lack of vigilance and engagement are held responsible for the “misbehavior” of their children:

*Some people say that the father never taught him good manners so he has ended up getting the disease.* (Participant in an FGD of rural women, Zambia)

Further, if a family member is known or assumed to be HIV-positive, there is a sense of transference of HIV-positive

*“The parents of the orphan died of HIV/AIDS. The aunt and cousin mistreat the orphan. No food is left or given to the orphan to eat and the aunt with the cousin gives the orphan household work to do, but them, they are just sitting”*  
—Urban girl, aged 13, Zambia



status and the “immoral” behaviors assumed to have caused it to the entire family. As expressed by an Ethiopian rural woman, “Because their son died due to AIDS, they will think every member is infected.”

*In families it is the same like a thief. If there is a thief in the family everybody is a thief. So, if there is someone with the disease, then everyone also is a prostitute. Everyone has HIV/AIDS. No one gets good remarks when you have AIDS; everything is insults.* (Rural man, Zambia)

*There are some who said that family was a prostitute, they aren't settled down.... Some would say the whole family is affected while it's only one who had AIDS.* (Participant in an FGD of rural women, Tanzania)

In all three countries, family members face much of the same differential treatment—physical and social isolation, gossip, and loss of livelihood—as people infected with HIV, as this quote of a woman with HIV illustrates:

*My neighbors are not willing for my children to watch TV in their house.* (Urban woman, Ethiopia)

As a result, families may also face reduced livelihoods and job opportunities. Families that rely on small businesses often lose customers who are reluctant to buy food from the family:

*Some people might have been buying milk... from that family. They stop that if it is discovered a relative or a member of that family who lives in that same house died of HIV. Besides, people will stop buying anything from the suspected person's family if the family has a shop, or they stop borrowing materials and the family will be isolated and left alone. Whether the HIV-contracted person is alive or dead, people are frightened to share things with such kind of a family.* (Rural man, Ethiopia)

Children of PLHA are especially stigmatized. As women in rural Zambia describe, “Other people will start teasing her that she also has AIDS. The child will always be in worry and misery.” As a consequence of their association with HIV, regardless of their HIV status, children of PLHA are often considered dirty and unwanted. Children, in turn, internalize these negative reactions. In group discussions, orphaned urban and rural children in Zambia say, “It's my fault because I don't have parents,” and “I was not supposed to be born.”

This theme is the strongest in Zambia, perhaps due to the high prevalence of HIV and AIDS among adults and a growing number of AIDS orphans. In the communities, orphaned children are often blamed for their parents' behavior. Respondents recognize this and feel that such mistreatment will lead these children into a life of reckless abandon and carelessness, thus continuing the cycle of HIV:

*So these children being blamed for their parents' behavior.... They start living in fear, even at school he will not concentrate properly... because of the mistreatment they are affected, will also become very reckless about their life, in the end they are affected.* (Participant in an FGD of urban women, Zambia)

Children are often reminded of their parents' behavior and death when they make mistakes or are punished by their guardians. They often bear the brunt of family stress, which is fuelled by poverty or lack of resources:

*I was taken to the relatives and I used to be mistreated. Whenever I made a mistake I was beaten, told all sorts of insults and always told I am an orphan. They used to remind me about my parents and I just cried.* (Urban girl, Zambia)

## 5.4 Individual and family strategies for coping with stigma

People living with HIV and AIDS, as well as affected families, use many different strategies for coping with the experience and impact of stigma. In Ethiopia, coping is described as a process where the strategies employed change over time, and vary by short-term versus long-term realities and circumstances.

Several coping mechanisms emerge in the data. The first is disclosure of status in order to seek support from family, friends, support groups, counseling and other services. A woman living with HIV explains the importance of this support:

*I was seriously ill. My aunt came to see me. I disclosed to her that I was suffering from AIDS. She tried to console me and promised that she would be on my side and gave me a lot of information on AIDS. I was extremely delighted and encouraged by the advice that my aunt gave me. (Urban woman, Ethiopia)*

At the same time, denial, non-disclosure of status and hiding away the person living with HIV can also be a way of coping. Non-disclosure can be part of denial, or as described in the data, a method to protect against stigma. Another means to ward off stigma, as described by a few people with HIV in Ethiopia, is moving to a new place where their HIV status is unknown.

Another coping mechanism is for people with HIV and AIDS to join with other PLHA, whether informally, or by organizing or joining existing networks of people with HIV and AIDS, as described by this woman with HIV:

*We did not know each other, but when we saw each other one of us crying we knew then we had the same problem. We used to talk about this whenever we met; we also used to visit each other. (Urban woman, Tanzania)*

### Summary of coping strategies used by people living with HIV and AIDS and their families

- Disclosing an HIV-positive status in order to seek support
- Denying or not disclosing an HIV-positive status if stigma is anticipated
- Participating in PLHA networks or seeking work in the arena of HIV
- Directly challenging stigma publicly and in everyday life
- Seeking explanations and comfort, for instance in witchcraft or religion

Some PLHA cope by taking an active role in HIV and AIDS education and counseling, reaffirming a sense of purpose in life by being able to help others. In describing her work teaching about HIV and AIDS, an urban woman with HIV in Ethiopia explains, "I felt pride in that I have a social responsibility to accomplish in my life."

Our data also shows that some people with HIV take this a step further to actively challenge stigma in daily individual interactions, as well as publicly:

*I do advise people who isolate me to learn from their mistakes... recently a woman who lives in our compound avoid to have social affairs and sharing toilet with us... One day I told her that it is her right not to participate in social affairs and share the toilet with us, but... that HIV/AIDS doesn't transmit through eating together and sharing toilet. After awhile, she realize it and asks our apology and starts to share social affairs with us. (Urban woman, Ethiopia)*

Other coping mechanisms involve searching for comfort or explanations. Many people with HIV in all three countries turn to religion and prayer for comfort, solace and support:

*They prayed for me. I felt relieved. I had a lot of worries... the church servant approached me*

*and gave me hope...all brothers and sisters congregated and prayed for me. (Urban woman, Ethiopia)*

Others cope by searching for an explanation for HIV infection other than sexual transmission. The most common alternative explanations are witchcraft (Zambia and Tanzania) and being given HIV by God (Ethiopia). An explanation of witchcraft provides some degree of protection against stigma, as the source of infection is now outside the control of the individual. Both explanations offer hope for a cure:

*Respondent: When someone has HIV, he or she hides it, once he falls sick; he searches for some other reasons to ascribe to... like being bewitched.*

*Interviewer: Who searches for the reasons?*

*Respondent: The patient, perhaps even the family. It is a shame; they feel shameful that their son or daughter has AIDS. They find this shameful because people with this disease are regarded as being prostitutes; their daughter will be deemed a prostitute, putting a flaw in their family. Therefore, the parents may opt to say she has been bewitched. (Urban woman, Tanzania)*

Often these strategies are employed sequentially over time. However, different strategies may be used simultaneously, often depending on location. For example, PLHA may gain support and strength by disclosing their status and joining a support group that is at a distance from their place of residence, while simultaneously employing non-disclosure with their family and in their immediate neighborhood. While these coping mechanisms do not all necessarily contribute to the broader aim of reducing the spread of HIV, they are an individual defense mechanism against stigma. And some, such as education and counseling efforts of people with HIV and AIDS, provide a good basis on which to build programs to enhance skills to challenge stigma.

## 5.5 Consequences of stigma for programs

Our data confirms that stigma impedes people's willingness and ability to adopt HIV preventive behavior, access treatment and provide care and support for people living with HIV and AIDS.

### 5.5.1 Prevention efforts

We find that the fear of stigma impedes prevention efforts, including discussion of safer sex with one's partner, condom use, and preventing mother-to-child transmission. Strong beliefs about the association of HIV with "immoral" behavior make people dissociate themselves from "others" who they perceive engage in such activity. This separation between "us" and "them" makes people reluctant to associate with HIV in any way, even for prevention. This process allows people to avoid confronting their own risk and adopting preventive behaviors:

#### Summary of findings on consequences of stigma for programs

- Private and public disclosure of HIV status is limited
- Preventive behaviors, such as using condoms, discussing safer sex with a partner, and the prevention of mother-to-child transmission, are not adopted
- Care and support is often undermined when accompanied by stigma, for example in the form of judgmental attitudes and physical isolation; or in terms of passing on an HIV patient from provider to provider because none are willing to administer treatment
- People with HIV and AIDS may experience stigma when care is reduced over time, even when this occurs because family caregivers become fatigued and exhaust economic resources on care
- PLHA with HIV and AIDS may delay care until very ill and travel farther or pay more in search of non-stigmatizing care

*I think people are just talking that 'AIDS kills, it is horrible,' but they are not following any of the advice on what they should do to avoid getting it; is there any fear there? Nobody is caring. Everyone sees it is not for them; they won't get it, someone else will, for this and that reason, but not me (Participant in an FGD of urban women, Tanzania)*

In some cases, in addition to or instead of adopting preventive behaviors themselves, people turn to faith as a means of protection that allows them to ignore their own risk:

*I am sure it won't infect me. I take care of myself. Additional to this, I have faith in God; due to this I won't be infected with this disease. (Rural man, Ethiopia)*

Certain preventive behaviors are highly stigmatized and thus unlikely to be widely or openly adopted. In all three countries, people are unwilling to suggest safer sexual practices to a partner for fear that they will be suspected of infidelity, of being HIV-positive, or they will inadvertently disclose their status if they are HIV-positive. For instance, condom use, or its suggestion, is associated with infidelity or infection. Women, in particular, are unable to negotiate safer sexual behaviors. Those with HIV express a great fear of abandonment and abuse if they reveal their status to their partners, further diminishing the likelihood of condom use or other safe sexual behavior within these relationships.

Our data also confirms previous research that found that fear of stigma and inadvertent disclosure of one's HIV status inhibits women's participation in Preventing Mother to Child Transmission (PMTCT) programs (Bond and Nubani 2000; Nyblade and Field 2000; Tlou et al. 2000). As indicated in the quote below, any child-rearing behavior that is out of the ordinary, such as formula feeding, raises suspicions about the woman's HIV status and makes her vulnerable to stigma and discrimination:

*Maybe I have already got the viruses and my husband doesn't know. That means if I deliver a child, I will have to breastfeed him or her as usual... people time to time they are asking you, 'Why aren't you breastfeeding the child?' Thus it becomes troublesome. (Participant in an FGD of urban women, Tanzania)*

As several of these testimonials illustrate, the fear of stigma is an obstacle to the adoption of safe and protective behavior, even when modes of transmission and prevention are known.

### 5.5.2 HIV testing and disclosure

Our data indicates that utilization of VCT services and disclosure of HIV status are constrained because of the anticipated stigma and actual stigma experienced by people living with HIV. As explained by an urban man in Ethiopia, "People fear to take the blood test because if their results [are] positive, they think that people will isolate and segregate them." While respondents in all three countries strongly favor testing, see some benefits to it and feel people with HIV should disclose their status publicly, they recognize that few do so because of the potential negative consequences of disclosure of a positive status:

*Those who come for blood test don't want to be known by others because they expect*



*social avoidance. They fear to be pointed fingers by others. Due to this they keep it secret.* (Urban man, Ethiopia)

*If you see someone being mistreated because they are HIV infected, it is obvious the same will happen to you when it is known you are HIV-positive.* (Urban man, Tanzania)

Testing is further constrained because of the fears that the process of going for a test, or the result of that test, may not remain confidential. While some fear that counselors and other health care professionals may not maintain confidentiality, the principal fear is of inadvertent disclosure simply because someone may see you waiting at the clinic or VCT center. As a man in urban Zambia explains, “Most people, they think if they go to the clinic, say for instance for a test, they think that the results will be exposed to other patients.”

The strength of this fear also prevents those who do test from recommending VCT to others, for fear it may lead to assumptions that they are HIV-positive. An urban woman in Zambia explains that though she herself had been tested, she would not encourage others to do so because people might assume that they have HIV. Even simply discussing the possibility of testing can result in negative consequences:

*I saw my classmate crying... and she told me that she gets ill constantly.... Then I told her that I know people who do HIV blood examination and that it is better to try it.... I regretted about the talk we had as she told the other students that I told her to take HIV blood test and they considered that as an insult.... Since then she and me haven't talked. The students rejected me only because I talked about HIV blood test. Thus, you can guess what would happen to me if I disclosed my status to my school friends, and I wouldn't do that unless I decide to leave the school.* (Urban woman, Ethiopia)

In all three countries, those who do test rarely disclose their status beyond a limited number of trusted individuals, despite the widespread belief that disclosure should be encouraged. People with HIV fear disclosure will lead to generalized stigma and also result in more specific repercussions, including being blamed for bringing the infection into the home and losing the support of a partner and family as a consequence:

*If I am infected with AIDS, I will not disclose because if I disclose that I am HIV- positive, people will hate me.* (Rural woman, Ethiopia)

*I have been chased away by my husband, I have gone to our own [natal] home, [but] even there they have chased me away [when] I beg for assistance.* (Urban woman, Tanzania)

While the data shows that limited private disclosure does occur, public disclosure is rare and is often met with both harsher private and public consequences:

*Because I shared my life experience... on TV, many of my relatives became very angry and insulted me.... I took a taxi and a young man was sitting by me. He saw me and then he changed his seat and I heard him telling others that he saw me on TV disclosing that I was HIV-positive.* (Urban woman, Ethiopia)

Further, data from all three countries shows that, when resources are constrained and people perceive that resources are externally available for people with HIV and AIDS, then those who disclose their status and play an active role in interventions can suffer added stigma in the form of suspicion of their motives for such involvement.

It is clear that stigma and discrimination—experienced, observed and feared—seriously impede prevention, testing and disclosure, in addition to placing an immense burden on people with HIV. People living with HIV and AIDS, as well as

the community, recognize the consequences of this with respect to preventing further spread of HIV:

*If [she] tells him, [she] will be left... therefore she continues as usual in her secrecy. Therefore, you find those viruses continue to be spread because if she tells her husband, he will chase her [away].* (Participant in an FGD of urban women, Tanzania)

### 5.5.3 Care and support

In a context where anti-retrovirals are not widely available, the care and support that people with HIV can need is often intensive and over an extended period of time. Data shows that while people with HIV and AIDS do get care from their family and the health care providers, this care can come with stigma. This stigma is most intensive in the home and health care settings—the two places where most care occurs and where expectations of care are high.

#### 5.5.3.1 Care, support and stigma in the home:

Care for PLHA can be accompanied by judgmental attitudes about the potential mode of transmission. Because of the perception that HIV is transmitted through “immoral” sex or otherwise deviant behavior, families are often inclined to blame PLHA for their ill health and reduce care as a result:

*Instead of [the family] taking care of you, they start blaming. You may be affected in two ways: in terms of lack of care and in terms of stress.*  
(Urban woman, Tanzania)

Given the belief discussed earlier that young people are especially promiscuous, youth may be particularly blamed for their HIV infections. Combined with a belief that adults, particularly adult women, lead responsible, moral lives, this blame can mean that youth who have HIV and AIDS receive less care and support than do older people:

*If a young woman contracts AIDS, if she never used to [listen] to their advice, the parents don't*



*take care of her. She is usually rebuked. But an older woman has a lot of people she knows... They can't rebuke her.* (Participant in an FGD of rural men and women, Zambia)

Resources like medicine, transport to medical services, food, and other amenities may be withdrawn because of the common perception that people with HIV are hopeless and near death. This perception also can lead families to believe that caring for someone with HIV is a waste of time and resources:

*She asked her brother to take her to hospital. He refused by telling her that she was hopeless. He told her not to bother people and he does not want to waste money on her. He told her she was HIV/AIDS patient and does not want to help her because he felt that she was useless and openly told this to her.* (Urban woman, Ethiopia)

At an extreme, the denial of care can result in abandonment. In urban areas of all three countries, family members with HIV and AIDS, including children, were often sent back to the village or shuffled among extended family members.

Our data shows that poverty exacerbates denial or withdrawal of care and support. In a situation of poverty, households often have to make hard



choices about allocating constrained resources and care. Therefore, someone with HIV who is seen as unproductive or near death may find resources withdrawn. In some cases, for instance in Zambia, poor PLHA in need of medical care may also experience isolation as family members avoid the emotional guilt they feel for not being able to provide the care they need. These actions may not be intended as stigmatizing, but may be experienced as such by the person with HIV.

Similarly, at least some of the decrease in care for those with HIV occurs as a response to the very real fatigue of caring for PLHA. We find many cases where family members start out providing care, support, food and medicines. As time goes on, however, caregivers suffer from the emotional, physical and financial burden of caring for someone with HIV. Eventually, their support may decrease, and sometimes they feel increasing resentment or anger towards the person with HIV. Whether or not this behavior is intended to be stigmatizing, it is often experienced as such by the person with HIV:

*She [mother] doesn't bring [medicines and fruit] like she was doing in the beginning. You can even ask for some money for Panadol and she'll give it to you with sneers or will tell you, 'I have no money.'* (Urban woman, Tanzania)



Women disproportionately bear the burden of care for relatives who are HIV-positive, simply because in all three societies studied, women are the primary caretakers for all household members. Providing care is part of their socially-expected role in the home. However, women become exhausted and may stop caring for family members with HIV, despite what society expects them to do. Respondents themselves acknowledge that this is the case:

*Us women, we run away; if I see my husband sick for five years, I will surrender and will say you have your relatives, they should also come and nurse you.* (Participant in an FGD of urban women, Zambia)

**5.5.3.2 Discriminatory care and support in the health care setting:** In the health care setting, discriminatory care and support for those with HIV or AIDS is manifested through longer waits for service, being shuttled from provider to provider, not being given treatment or equal care to those with other illnesses and being scolded by providers. In Tanzania, for example, three months after learning they were HIV-positive, some PLHA reported that nurses would pass their case on to another nurse for treatment (especially for injections). In the three sites, while most doctors do not report treating their patients with HIV and AIDS any differently than other patients, several clients do report receiving less aggressive treatment than an HIV-negative patient:

*When the nurse sees in your book and concludes that you are HIV-positive, she will shout at you like you are wasting medicine, giving [it to] these people who are HIV-positive.* (Urban woman, Zambia)

Stigma and discrimination are likely to be higher—and the level of care less—for poor versus rich people with HIV. At the most basic level, this is simply because the poor cannot afford health care,

### Text Box 6: Provision of Care and Support of HIV-Infected People

Despite stigma, respondents expect that families and those in health care settings should take care of people living with HIV and AIDS, which they largely do. As a rural Zambian man notes, *“It is not a burden because that person is your relative, and you have to be at his or her aid.”* Over two-thirds of the Ethiopian survey respondents, for example, feel that people with HIV and AIDS should go to the family for care and support. Survey respondents also state that they would be willing to care for male or female relatives with HIV and AIDS in their own household. Across the three countries, data shows that despite stigma and discrimination, families are supportive primary caregivers for PLHA. As stated by these urban women in Tanzania, *“You may be a victim, but your family takes care of you and accompanies you when you go for counseling and advice. You will not feel lonely.”*

Family and friends also provide crucial psychological support and hope to people living with HIV and AIDS:

*My hope was darkened upon hearing the death of my friend. I mentioned what I felt to my friends. They said, ‘We are not the only ones destined to die. This is everybody’s destiny.’ And they said that ‘We should not feel any different from others when someone living with HIV/AIDS passes away.’* (Urban woman, Ethiopia)

Expectations of good care—and evidence that such care exists—are also evident in the health care setting. A majority of Ethiopian survey respondents feel that the health care system should provide care to people living with HIV and AIDS. Seventy percent feel that people with HIV and AIDS should get more care from the system than those with other chronic diseases; two-thirds feel that people with HIV and AIDS should go to the health center for care and support, and 95 percent say that health care facilities should offer care for people with HIV and AIDS. Qualitative data from clients in Zambia and health providers in Tanzania show that the health system does, in some cases, provide good and conscientious care:

*At the clinic these days people are treated much better. There is less stigma. Most of the nurses... are becoming counselors and even caregivers, so the treatment is much better.* (Rural man, Zambia)

*If you go to a hospital, they tell you not to give up hope. You can live long if you follow the instructions that you are being told.* (Urban woman, Tanzania)

Although stigma clearly exists in health care settings, there is also ample evidence that families, communities, and health providers with good intentions provide quality care and support. Programs, by supporting caregivers in the home and health care setting through counseling, information on care of PLHA, and financial support, can build on these good intentions to realize non-stigmatizing care.

or equally good health care, as the wealthy. There is also some evidence, however, that the poor with HIV are stigmatized precisely because they are poor and marginalized, and that the rich get better care in the health system and in the community because of the high social status that their wealth bestows on them:

*Mostly the poor are overlooked due to their poverty or when they go to medical institutions. The rich are given [more] attention than the poor people because of his status as a rich person.* (Urban man, Zambia)

Health care providers may be reluctant to give care because of their genuine fear of HIV transmission on the job. As this health care provider says:

*I don’t want to be taking care of a patient and putting myself at risk; so for that matter if you don’t know then all of us will die of HIV/AIDS. So it’s important for us to know [our patients’ HIV status]; at least to take the precautions as far as transmission is concerned* (Urban man, Tanzania)

Data also shows, however, that some health care providers are more fearful of stigma if they contract HIV than of the disease itself. Even if the virus is transmitted in the course of treating patients, the association of HIV with “immoral sex” is so pervasive that they feel certain they will be reproached and scorned by family and the community. As a health care provider in Tanzania explains, *“If you get infected in the [operating] theater, nobody will know that you are infected in the theater. They will think that this guy was very promiscuous.”*

Regardless of the motivation for stigma in the health care setting, one serious consequence is that PLHA actually avoid or delay seeking care for HIV or related illnesses in order to avoid stigma and discrimination.

Data from Zambia shows that people even may delay seeking care for other diseases such as tuberculosis and herpes because, as opportunistic infections of AIDS, they are seen as synonymous with HIV and AIDS. In all three countries, the fear of association with HIV is so great that patients with HIV sometimes claim to have a different affliction, and even refuse proper medication in an effort to mask their true illness, as this example shows:

*I went to a clinic. I came across a patient and I talked to him. He told me he has gastritis, though it was AIDS. He asked me too and I told him that I am AIDS patient. We were given similar medicine and the guy got shocked, for he felt that people would know him. He asked the doctor to change the medicine.... What I learned is that people really go out of their way to hide their HIV status. (Urban woman, Ethiopia)*



## 6 Conclusions and Recommendations

### 6.1 Summary of findings

The findings presented here synthesize key themes in the data from across the three countries. More in-depth analysis of these issues, as well as additional analysis on areas not covered in this report like urban-rural differences and the findings from the country sub-studies, can be found in the individual country reports.

Stigma is a complex phenomenon that is deeply intertwined with social values, fears around sex and death, and gender and social inequity. Yet, our findings show that it is possible to disentangle stigma. The causes and consequences of stigma are similar across all the countries' study sites. Some key reasons that stigma persists are a lack of in-depth knowledge of HIV and AIDS that allows fears of casual transmission to endure, strong norms about "improper" and "proper" sex and its association with HIV, and a lack of recognition of stigmatizing attitudes and behavior.

An overarching theme is that contradictions co-exist within individuals and communities. People who believe it is important not to stigmatize people living with HIV in fact do. Individuals simultaneously maintain correct and incorrect knowledge about HIV. Even those who know that

HIV is not transmitted through casual contact continue to have doubts and behave as if it is. People express sympathetic attitudes toward people with HIV together with stigmatizing ones. Families, health care providers and religious leaders provide genuine care and compassion for people with HIV and AIDS, while concurrently stigmatizing them. People are also ambivalent about testing and disclosure, which are described as positive and necessary but also as uncommon and difficult.

Widespread stigma clearly impedes programmatic efforts for HIV prevention, testing and disclosure, as well as care and support, underscoring the urgency of reducing stigma. The process of disentangling stigma reveals many opportunities for interventions. The findings clearly show that everyone and all groups, no matter where they live or what they do, have a role to play in reducing stigma.

### 6.2 Critical programmatic elements to tackle stigma

Our research points to five critical elements that need to be addressed by all programs aiming to tackle stigma.

### 6.2.1 Create greater recognition about stigma and discrimination

The data shows that while people stigmatize and discriminate, and even if they are consciously aware that they are doing so, they lack an in-depth recognition of the dynamics of stigma. Thus, to tackle stigma, programs first need to create greater recognition within individuals, including ourselves, about the dynamics of stigma, namely:

- that stigma exists
- that stigma takes certain forms
- that it is harmful to ourselves, our families and our communities
- that we can make a difference by changing our own perspectives and actions

In other words, awareness-raising is needed at multiple levels. First, the disconnect between people's stated intentions not to stigmatize, and their stigmatizing attitudes, words and actions, points to a need to create recognition that stigma exists and recognition about how it is manifested in attitudes, language, behavior and actions. This applies to stigma experienced by people with HIV and AIDS as well as to internalized stigma.

Second, programs need to explicitly demonstrate why reducing stigma is beneficial, and show how stigma is harmful to individuals, families and communities. This is important because, even when people realize that they stigmatize, they may not make the connection between their individual actions and the impact of those actions on the epidemic and society.

Lastly, our research shows that people often do not realize that everyone can contribute to reducing stigma—it is not some overwhelming phenomenon where an individual has no role. Programs need to work with individuals and communities to enable them to recognize the role that each person plays in producing or reducing stigma in order to show them how they can make

a difference by changing their attitudes, language and behavior.

### 6.2.2 Foster in-depth, applied knowledge about all aspects of HIV and AIDS through a participatory and interactive process

Gaps in knowledge and a lack of in-depth information about HIV and AIDS fuel the fear of casual transmission, leading to actions that are stigmatizing and the belief that people living with HIV and AIDS are non-productive members of the community. Interventions need to address these gaps by providing up-to-date, accurate, in-depth information about all aspects of HIV and AIDS, particularly:

- how HIV is and is not transmitted
- the difference between HIV and AIDS
- what it means to live with HIV, including the fact that opportunistic infections are treatable in people with HIV and AIDS
- the longevity of a person with HIV
- that people with HIV are productive members of society
- how to care for and support people with HIV and AIDS

All of this information needs to be provided through an interactive, participatory process, which allows for a period of reflection and an opportunity to come back and ask questions. This process will allow people to examine their own experiences, concerns, and perceptions of risky situations and actually apply new knowledge in their daily lives.

### 6.2.3 Provide safe spaces to discuss the values and beliefs that underlie stigma

Values and beliefs about appropriate behavior and fears about death, as well as entrenched social inequity, fuel stigma. Interventions to reduce stigma must begin to tackle these difficult and often taboo issues. Providing safe spaces for

individuals and groups to explore the link between stigma and underlying values and beliefs is one way to do this. Our data suggests that interventions cannot tackle stigma without creating an opportunity for individuals and communities to:

- openly discuss sexual taboos and sexuality safely
- voice and discuss the fear of death, particularly of premature, disfiguring and painful death
- discuss and understand the context of social inequity, especially the interaction of gender and poverty with stigma

By opening up discussion and providing a safe and non-threatening space to explore these issues, interventions can begin the long-term process of enabling individuals to create and adopt non-stigmatizing principles, values and norms.

#### **6.2.4 Find common language to talk about stigma**

An essential step in designing interventions to reduce stigma is finding common language to talk about it. This study found that terms used by programmers, policymakers, and researchers to describe the concept of stigma were not necessarily understood by community members. This is particularly the case when stigma does not feature linguistically in local languages and is therefore difficult to translate. Programmers need to invest time in developing a common vocabulary around stigma with the communities in which they work (MUCHS and ICRW 2002). When equivalent terms do not already exist, we found that pictures, vignettes and stop-start dramas were useful techniques to stimulate discussion about stigma.

#### **6.2.5 Ensure a central role for people with HIV and AIDS**

People with HIV and AIDS have a central role in stigma reduction at any level of intervention and

provide a strong basis on which to build successful programs. Bearing the brunt of stigma, PLHA have the life experience and knowledge needed to design appropriate stigma-reduction responses. In addition, as detailed in a recent review (Brown et al. 2003), interventions which involved direct interaction between people with HIV and AIDS and stigmatizers indicate some success in lowering stigma. Several of the underlying causes of stigma identified in our report—fears of and misconceptions about casual transmission of HIV, the belief that PLHA are somehow different, and the belief that HIV equals immediate death and disability, rendering people with HIV and AIDS non-useful members of a family or community—point to the critical role PLHA have in dispelling the myths that allow stigma to persist. Working to fight HIV and stigma is also an empowering activity that gives hope to people with HIV, and is also one means to overcome internalized stigma.

At the same time, it is essential to ensure that the involvement of people with HIV and AIDS is done in an ethical, totally voluntary and contextually-appropriate manner. When HIV infection and stigma occur in a context of poverty and related social and gender inequalities, as is the case for many of the people living with HIV and AIDS in the three countries studied here, interventions need to carefully consider the constraints that people with HIV and AIDS face. In particular, interventions need to ensure that involvement in stigma reduction activities does not add an additional burden for PLHA. Further, data from all three countries shows that those who disclose their status and play an active role in interventions can suffer added stigma when people suspect their motivation is to obtain resources available for people with HIV and AIDS. Programs must take such issues into account in structuring the type and process of PLHA involvement in a community.

### 6.3 Implementing programs to reduce HIV-related stigma

While the research points to the need for all institutions, programs and individuals to address stigma, the focus of our study has been understanding stigma at the community level. At this level, five groups emerged most strongly as having a key role in stigma reduction.

#### 6.3.1 Families caring for people with HIV and AIDS

The study shows that while there is a good base of compassionate caring in many families, it is often accompanied by stigma. The following steps can be taken to support families to reduce stigma in the home and should involve all family members, particularly men, to encourage greater sharing of the burden of care within the household:

- *Provide families with practical knowledge and skills for caring and counseling.* This should be coupled with up-to-date and accurate information on HIV and AIDS, which can decrease stigma in the household by reducing fears of transmission in the course of providing care.
- *Help families recognize stigma within the household* to close the gap between good intentions for compassionate care and the often stigmatizing effect of the care given. This will reduce stigma and help build understanding, respect and sensitivity towards people living with HIV and AIDS.
- *Supplement and support limited financial and emotional resources.* Poverty, lack of service options (like medical, home-based, or hospice care, or counseling) and a disproportionate burden of care on women all exacerbate stigma and can lead to circumstances where caregivers unintentionally stigmatize the person living with HIV. Providing poor households with financial resources and services necessary to provide non-stigmatizing care, and all

caretakers with emotional support and options for respite from the fatigue of care, will help reduce stigma within the household.

#### 6.3.2 Non-governmental organizations (NGOs) and other community-based organizations (CBOs)

Our study points to some basic underlying actions that NGOs and CBOs can take to reduce stigma:

##### ■ *Train own staff*

Before starting any interventions in the community, these groups need to first focus on training their own staff to:

- Recognize stigma and its causes and manifestations
- Acknowledge that anyone can harbor conscious or sub-conscious stigmatizing thoughts or attitudes
- Consider and analyze own experiences of stigma, including as stigmatizer or stigmatized (directly or through association with people with HIV)
- Realize that anyone can address stigma in small or large ways

Our experience shows that NGO staff already working on issues of HIV and AIDS may need such training because they have not had a chance to reflect on and analyze the issue of stigma *per se*.

##### ■ *Incorporate ways to reduce stigma in all activities and interventions*

Our work shows that HIV-related stigma can affect all aspects of life in a community. Thus, to address stigma at a community level, NGOs ideally should incorporate stigma reduction in all programs. They can broaden the scope of their stigma work indirectly by training as many of their staff as possible, as outlined above. These trained staff, in turn, will be equipped to address stigma in their ongoing work.

- **Critically examine own communication materials to ensure that:**

- Messages about HIV and AIDS are not fear-based, since those are likely to increase fear of, and thus stigma against, PLHA
- People with HIV are not portrayed as negative caricatures, such as near-death or helpless victims
- The information on HIV and AIDS provided is up-to-date, accurate, complete, and comprehensible
- Particular groups are not singled out or portrayed as vectors of HIV (for example, young, single women)

### 6.3.3 Faith-based organizations, religious leaders and congregants

Religious groups have a central role to play in reducing stigma and can take the following steps:

- **Develop non-stigmatizing service provision and stigma reduction programs**

In many communities faith-based organizations provide many, if not the majority, of HIV and AIDS-related services, such as counseling, education, health care, care for orphans and home-based care. In addition, PLHA and their families turn to religious leaders and congregations to provide emotional and spiritual support. Therefore, faith-based organizations and religious leaders need to take the same steps detailed above for NGOs and CBOs to train their staff, incorporate stigma reduction into all activities and examine their communication materials.

- **Emphasize non-stigmatizing messages in sermons, religious services and other faith-related activities**

Faith-based organizations, religious leaders and congregants can play a central role in perpetuating stigma—or mitigating it—by the way they portray HIV or people with HIV in their religious messages and communication

materials, and by the way PLHA are treated in places of worship. Thus, faith-based organizations can reduce stigma by:

- Modifying the language of their religious activities and sermons to ensure that it is non-stigmatizing and non-discriminatory
- Accepting and supporting PLHA openly in their congregations
- Using religion to encourage others to accept and support PLHA, by, for instance, invoking non-stigmatizing support as an essential part of “good” religious practice

### 6.3.4 Health care institutions

Our research shows that many health care providers can have stigmatizing attitudes and thus behavior towards PLHA. At the same time, it is clear that health-care providers feel at risk because of their exposure to the virus in the process of providing services. Any efforts to reduce stigma in the context of health care institutions, or by health care providers themselves, need to address both of these issues. Interventions can:

- **Incorporate training on non-stigmatizing attitudes and care in medical training**

Trainers need to educate both new health care workers and current providers.

- **Recognize and minimize workplace risk**

Interventions to reduce stigma in the health care setting need to acknowledge health workers’ fears, assess their risk in the workplace, and then seek ways to minimize this risk, through, for instance:

- Ensuring implementation of universal precautions
- Providing counseling for trauma faced by caregivers themselves, recognizing that health workers are community and family members and face the same challenges
- Providing post-exposure prophylaxis



### **Text Box 7: Tools for Stigma Reduction**

In addition to identifying key elements and groups for interventions to reduce stigma, the research process also uncovered a gap in available tools for NGOs and communities to address stigma. CHANGE/AED is leading a collaborative effort in all three countries to develop such materials to fill this gap.

The result will be an “anti-stigma toolkit,” a collection of tools and materials to create and deepen the understanding of stigma, and provide a process and the capacity to then address it. The toolkit is structured as a participatory, problem-based curriculum, centered around a series of exercises. It was developed through interactive, participatory workshops in all three countries, with a total of 75 participants from 50 NGOs.

The toolkit aims to:

- Address the need for a common language for recognizing stigma
- Assist in resolving contradictions such as those between intentions and behavior
- Clarify values and competing priorities of individuals
- Reduce unintended consequences of stigmatizing actions
- Bring taboo subjects like sex, sin and death into the open
- Strengthen the capacity of people living with HIV and AIDS to challenge stigma in their lives
- Provide a process to determine appropriate and feasible individual and community responses to stigma
- Provide comprehensive, flexible tools for organizations to strengthen staff skills and develop or strengthen interventions to reduce HIV-related stigma

The toolkit works by raising the issue of stigma among participants and challenging them to confront it. It tackles stigma from the perspective of both the “stigmatizer” and the “stigmatized,” encouraging people to reflect on their stigmatizing attitudes and behaviors and providing people with HIV and AIDS and their families space to examine stigma and develop skills and strategies to deal with it.

The central themes the toolkit addresses are based on the findings from this research:

- Root causes
  - Naming the problem of “stigma”
  - Overcoming incomplete knowledge and fear
  - Sex, morality, shame and blame
- Working with affected groups
  - Living with and caring for PLHA in the family
  - Coping with stigma
  - Stigma and vulnerable children
- Action planning—developing planning tools and approaches
  - Prioritizing and selecting issues
  - Developing intervention strategies, activities and a behavior change framework
  - Working with partners
  - Strategic planning, monitoring and feedback

The toolkit is currently in an experimental stage. Future research plans include modifying modules for additional groups and testing and evaluating the toolkit in one or more of the sites that participated in this study.

### 6.3.5 Media

Our study found that language and information on HIV and AIDS have important effects on the experience of stigma. The media, then, is a powerful tool by virtue of its tremendous reach and ability to influence people's opinions and actions. Institutions working with the media, and the media itself, can make messages and information about HIV and PLHA non-stigmatizing by:

- **Examining the language of media messages**  
Media professionals can examine and modify the language used in media to ensure that it does not portray HIV and people with HIV in negative, stereotypical ways.
- **Providing accurate information**  
Media can be used to provide up-to-date and complete information on HIV.
- **Not reinforcing misperceptions**  
In addition to providing correct information, the media can be used to negate misperceptions. At the very least, media and groups working with media can focus on ensuring that media messages do not repeat misperceptions.

## 6.4 Next steps

This study exposed the need for additional work related both to interventions and to further research. The following is not an exhaustive list.

### 6.4.1 Recommendations for interventions

1. **Develop indicators to measure stigma:** A set of validated indicators are needed to track the progress of efforts to reduce stigma. This and other studies provide a solid base on which to develop indicators by identifying the key domains of stigma. The next step is to test the indicators suggested by this body of work such that there is a comprehensive set of validated measures available to program staff.
2. **Test and refine tools for stigma reduction:** To date, very few tools are available that deal with

stigma in any depth. While the stigma-reduction toolkit (see text box 7) provides one set of tools, these are new and need to be tested and refined. This toolkit should be modified, and new tools should be developed.

### 3. Implement and evaluate stigma

**interventions:** Efforts to reduce stigma can be undertaken in either (or preferably both) of two ways: programs can address stigma through stand-alone interventions, or by integrating stigma reduction into other HIV and AIDS activities. However, because interventions to reduce stigma are relatively new, there is limited experience and virtually no published literature documenting what works and does not work in various contexts or with specific groups. Further work should test different approaches to stigma reduction. These approaches should be evaluated rigorously and documented thoroughly so that the most promising approaches can be widely disseminated.

### 6.4.2 Areas for further research

1. **Stigma among the wealthy and political, religious and business leaders:** This study was conducted in poor communities and captures the experience and understanding of stigma from the perspective of community members in poor areas. While our respondents had opinions about how the wealthy and those in power experience, cope with and perpetuate stigma, we did not collect data from these groups. However, in their positions as leaders, these groups influence social norms and actions that can either mitigate or perpetuate stigma. Additionally, only a few such leaders are open about their HIV status, and it is also important to understand better why this is the case.
2. **Young women, stigma and childbearing:** An emerging theme from the data is the dilemma faced by young people around childbearing in

the face of HIV. The constraints are particularly acute for young, married women with HIV who try to balance the stigma of being HIV-positive with the reality that childbearing is often their only route to social status and economic support. More work is needed to understand how HIV infection and its accompanying stigma shape the choices women make around childbearing in order to provide more appropriate services for HIV prevention, family planning, reproductive health and maternal and child health.

### **3. Interaction between stigma and increasing availability of HIV services:**

It is clear that stigma currently impedes the use of VCT, prevention of mother-to-child-transmission services, and treatment for opportunistic infections. Meanwhile, some emerging evidence suggests that stigma may also inhibit participation in treatment programs administered outside of the health care setting, such as the workplace. We need to know more about whether and how reducing stigma might improve participation in these programs. We also know little about what impact increased provision of existing services, as well as wider availability of anti-retrovirals (ARVs) in developing countries, will have on stigma. We need to investigate what changes need to occur within communities and within these services so that they more effectively reach greater numbers of people.

## **6.5 Positive foundations for change**

While much of our data paints a rather grim picture of deeply-embedded and accepted stigma

and discrimination against people with HIV and AIDS and other affected people, the findings also show that the complexity of stigma includes many positive, strong foundations on which to build stigma reduction. Interventions can build on:

- Good intentions not to stigmatize
- Individuals' recognition that a poor understanding of HIV and AIDS leads to stigma and discrimination, and their desire for more in-depth knowledge
- The widespread belief that families and medical services should provide non-stigmatizing care and support
- The caring, nurturing and compassionate side of religion and religious organizations
- The strength and experience of people with HIV and AIDS

Ironically, the very situation of devastation that HIV and AIDS is causing and has caused in Ethiopia, Tanzania, Zambia and other countries also provides the opportunity to effectively address the difficult underlying issues fueling stigma. Our research strongly shows that, in the face of the social, personal, economic, and political havoc wreaked by AIDS, communities and individuals are ready to face deep-seated norms and attitudes about sex, morality, death and social inequity, perhaps unlike ever before. It is now incumbent upon programmers, researchers, policymakers and individuals at every level of society to seize this opportunity and make a concerted effort to definitively address stigma and discrimination, and alleviate the burden of suffering it has added to the lives of people living with HIV and AIDS.



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