

Common at Its Core:

**HIV-RELATED**



**Across Contexts**

Jessica Ogden

Laura Nyblade

**Design:** Manu Badlani

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## Preface

This report is a synthesis of the collective work of multiple partner institutions and individuals in Ethiopia, Tanzania, Vietnam, and Zambia, as listed below in the citations for the individual country reports and the Africa-study synthesis. All quotes presented in this report are taken from the data presented in these reports.

Hailom Banteyerga, Aklilu Kidanu, Laura Nyblade, Kerry MacQuarrie, and Rohini Pande. 2004.  
“*Yichalaliko* (It Can Be Done)! Exploring HIV and AIDS Stigma and Related Discrimination in Ethiopia: Causes, Manifestations, Consequences and Coping Mechanisms.” Miz Hasab Research Center, Addis Ababa, Ethiopia.

Virginia Bond, 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.” Zambart Project and Kara Counselling and Training Trust, Lusaka, Zambia.

Sue Clay, Virginia Bond, and Laura Nyblade. 2003.  
“We Can Tell Them: AIDS Doesn’t Come Through Being Together. Children’s Experiences of HIV and AIDS-related Stigma in Zambia.” Zambart Project and Kara Counselling and Training Trust, Lusaka, Zambia.

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“Because it is the Disease of the Century: Understanding HIV and AIDS-related Stigma and Discrimination in Vietnam.” Institute for Social Development Studies, Hanoi, Vietnam and International Center for Research on Women, Washington, D.C., U.S.A.

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“Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia.” International Center for Research on Women, Washington, D.C., U.S.A.

We are grateful for the partnership of these exemplary colleagues whose insights and wisdom have contributed significantly to our own understanding of the issues discussed herein.

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# Table of Contents

<b>1. Introduction</b> .....	7
<b>1.1 What is HIV-related stigma?</b> .....	7
<b>2. Background</b> .....	9
<b>2.1 The studies: methods, sampling, analysis</b> .....	9
2.1.1 The Africa studies .....	9
2.1.2 The Vietnam study .....	10
2.1.3 The anti-stigma toolkit .....	11
<b>2.2 Important elements of context</b> .....	11
2.2.1 The HIV/AIDS pandemic .....	12
2.2.2 Economic situation: the relationship between poverty and stigma .....	13
2.2.3 The importance of religion .....	14
<b>3. Findings</b> .....	15
<b>3.1 The root causes of stigma: knowledge and morality</b> .....	15
3.1.1 The role of knowledge about HIV and AIDS and fear .....	15
3.1.2 The role of values, norms, and moral judgment .....	20
<b>3.2 Expressions and forms of stigma</b> .....	25
3.2.1 Physical stigma .....	25
3.2.2 Social stigma .....	28
3.2.3 Verbal stigma .....	29
3.2.4 Institutional stigma .....	29
<b>3.3. Consequences and impact of stigma</b> .....	30
3.3.1 Consequences of stigma for individuals living with HIV and AIDS .....	30
3.3.2 Consequences of stigma for the families of people living with HIV and AIDS (secondary stigma) .....	33
3.3.3 Consequences of stigma for HIV and AIDS treatment and prevention efforts .....	33

<b>4. Conclusions</b> .....	37
<b>5. Recommendations</b> .....	38
<b>5.1 Individual and structural change</b> .....	38
<b>5.2 Knowledge and fear about HIV and AIDS</b> .....	38
<b>5.3 Values, norms, and moral judgments</b> .....	40
<b>5.4 Involve people with HIV and AIDS as integral members of all programs</b> .....	42
<b>5.5 The way forward</b> .....	42
<b>References</b> .....	43

## Tables, Boxes and Figures

Table 1: Comparing Statistics on the HIV/AIDS Pandemic .....	12
Table 2: Comparative Statistics on Poverty .....	13
Table 3: Expressions and Forms of Stigma .....	26
Box 1: Defining Stigma .....	7
Box 2: Basic Facts About HIV Transmission .....	16
Box 3: Schematic of “Innocence-to-Guilt” Continuum .....	23
Box 4: Understanding and Challenging HIV Stigma: Toolkit for Action .....	41

## 1

## Introduction

**H**IV and AIDS-related stigma and discrimination together have long been recognized as one of the main obstacles to the prevention, care, and treatment of HIV and AIDS. Yet little has been done on a large scale to combat them. There are many reasons for this inaction, including the belief of many policymakers that stigma is hard to define and measure, making it difficult to design and implement interventions. Stigma, it is believed, is too cultural, too context-specific, and too sensitive to be addressed meaningfully. This report, a synthesis of findings from research in four countries, presents evidence suggesting that HIV and AIDS-related stigma is far less varied and context-specific than may have been imagined. In fact, there are many more similarities than differences across these contexts in the key causes of stigma, the forms stigma takes, and the consequences of stigma.<sup>1</sup> This finding opens a number of important avenues for intervention. It is time to make a concerted effort against stigma and discrimination in order to progress in the fight against HIV and AIDS.

The report begins by defining stigma and in Section 2 providing background about the

projects. Next, it discusses that, in spite of different contexts, the four countries where the studies took place share key features that shape the nature and forms of HIV-related stigma. Section 3 presents findings, focusing on the similarities across the four different country contexts, and is broken down into the following sub-sections: (1) understanding the root causes of HIV-related stigma; (2) an overview of the main expressions or forms that stigma takes; and (3) the consequences or impact of HIV-related stigma. Section 4 concludes with a discussion of the way forward and an overview of the two anti-stigma toolkits that grew out of the projects' findings: one that is suitable to many African settings; and one adapted from the first, which is tailored for Vietnam but suitable for adaptation elsewhere in the Asian region.

### 1.1 What is HIV-related stigma?<sup>2</sup>

Stigma is a complex social phenomenon involving interplay between social and economic factors in the environment and psychosocial issues of affected individuals. Goffman (1963) describes three types of stigma: (1) "abominations of the body," or stigma related to physical

#### Box 1: Defining Stigma

*In December 2003, UNAIDS posted a fact sheet on stigma and discrimination on its Web site ([www.unaids.org](http://www.unaids.org)), which provides a useful summary definition of both stigma and discrimination. The following is an excerpt:*

HIV/AIDS-related stigma can be described as a "process of devaluation" of people either living with or associated with HIV and AIDS. This stigma often stems from the underlying stigmatization of sex and intravenous drug use—two of the primary routes of HIV infection. Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Discrimination occurs when a distinction is made against a person that results in being treated unfairly and unjustly on the basis of belonging, or being perceived to belong, to a particular group.

<sup>1</sup> In this report, we equate "forms" and "consequences" of stigma with "discrimination."

<sup>2</sup> Text for this section has been drawn from Hong et al. 2004 and Nyblade et al. 2003.



deformities; (2) stigma related to “blemishes of individual character,” such as people who are considered to be weak-willed, to have unnatural passions, or to be dishonest; and (3) “tribal stigma,” or stigma relating to race, nation or religion, or membership of a despised social group. Because one typically inherits membership to this last group, tribal stigma can equally adhere to and affect all members of a family.

While Goffman focuses on the individual aspects of stigma, Parker and Aggleton (2003) offer a framework that emphasizes stigma as a social process that produces and reproduces relations of power and control. They also examine how stigma is used to turn difference into inequity—based on gender, age, sexual orientation, class, race, or ethnicity—allowing some groups to devalue others based on these differences. According to this analysis, stigma and discrimination are used by dominant groups to produce, legitimize, and perpetuate social inequalities, and exert social control through the exclusion of stigmatized groups, limiting the ability of the stigmatized groups or individuals to resist or fight the stigma.

In addition to an exercise of power, stigma can be a response to fear or risk or a threat of a disease that is incurable and potentially fatal (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 likely that stigma will result. Epidemics that present an overt threat to the values of a community are especially likely to evoke stigma

because stigma is used to “enhance or secure social structuring, safety and solidarity...or reinforce societal or community values by excluding divergent or deviant [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 individual’s responsibility. 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 an undesirable and unaesthetic death (Alonzo and Reynolds 1995; Cogan and Herek 1998; de Bryun 1998).

HIV and AIDS have all of the characteristics associated with heavily stigmatized medical conditions. They are associated with socially improper forms of sex and injection 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. HIV and AIDS also correspond to all three of Goffman’s stigma types noted above.

## 2

## Background

**2.1 The studies: methods, sampling, analysis**

Beginning in April 2001, USAID (through the CHANGE Project/Academy for Educational Development) and GlaxoSmithKline's Positive Action Program funded the International Center for Research on Women (ICRW) and its partners to undertake a program of research on HIV and AIDS-related stigma and discrimination. The objective of this research was to generate a foundation of evidence, through rigorous descriptive research, upon which to create tools and build interventions that would directly tackle the stigma and discrimination described. This research initially was conducted in Ethiopia, Tanzania, and Zambia—all sub-Saharan African countries hard-hit by the epidemic. These African studies ran from April 2001 through September 2003. In 2002, this work was extended to include a fourth country outside of Africa, Vietnam. The Vietnam study was conducted from August 2002 through February 2004. In all countries, the research was conducted by national research organizations with technical and managerial support from ICRW. All four studies, their methods, and analysis are described in detail elsewhere (see Bond et al. 2003; Banteyerga et al. 2004; Hong et al. 2004; Mbwambo et al. 2004). Additional support for the Africa studies was provided by USAID through the CORE Initiative, by the Swedish International Development Agency, and by the United Kingdom Department for International Development (DFID). In this section, we provide a brief overview of each study and its main output, and we introduce a toolkit for understanding and challenging HIV stigma.

**2.1.1 The Africa studies<sup>3</sup>****Partners**

Each country study was led by a local research institution. In Ethiopia, the research was led by the Miz-Hasab Research Center (MHRC); in Tanzania by the Department of Psychiatry, Muhimbili University College of Health Sciences (MUCHS); and in Zambia by ZAMBART (a collaborative project between the University of Zambia's School of Medicine and the London School of Hygiene & Tropical Medicine) and Kara Counseling and Training Trust (KCTT).

**Objectives**

The objectives of the Africa studies were to:

- (1) untangle the underlying factors that perpetuate or mitigate stigma;
- (2) document how stigma is influenced by the context in which it occurs;
- (3) analyze how stigma and discrimination is experienced by people with HIV and others who are affected by the disease;
- (4) understand how stigma and discrimination affects access to HIV prevention, testing, disclosure, care, and support efforts; and
- (5) recommend interventions.

**Methods and sampling**

An urban and a rural site in each of the three countries were selected for the community-based exploration of HIV and AIDS-related stigma and discrimination. In all cases, the communities selected are poor with high population density in urban areas and limited

<sup>3</sup> For an overview of all three studies and a synthesis of results, see Nyblade et al. 2003.

access to services, especially in rural areas. Employment is dominated by the informal sector in urban areas and subsistence farming in rural areas.

Data collection techniques were primarily qualitative, with the exception of a quantitative survey conducted in Ethiopia. Qualitative research methods across the three countries included key informant interviews, focus group discussions (FGDs), 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 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 nongovernmental organization (NGO) staff. The researchers purposively sampled all interview and focus group discussion respondents by sex and socio-economic status. In Ethiopia, researchers administered a survey questionnaire on knowledge, attitudes and behaviors around HIV to 202 rural residents and 200 urban residents who were systematically selected from existing official household lists. More details are available in Nyblade et al. (2003) and the country research reports (Bond, Chilikwela et al. 2003; Banteyerga, Kidanu et al. 2004; Mbwambo, Kilonzo et al. 2004).

In addition to the core, comparative community studies, each country also chose additional topics for sub-studies to reflect issues of immediate concern in their communities. These are outlined briefly below:

- ▶ **Ethiopia:** Men and women living with HIV and AIDS who belong to a NGO offering support to people with HIV and AIDS wrote diaries for six months, documenting their

experiences of living with HIV, including disclosure, interactions with family, community, peers, and colleagues, and how they coped with stigma.

- ▶ **Tanzania:** Voluntary counseling and testing (VCT) clients who were HIV-positive were enrolled in the study at the time of VCT and interviewed over a period of 10 months to learn about their experiences with stigma over time. The language aspects of stigma were explored at several levels: with linguists, HIV and AIDS experts, historians, and theologians on how to talk about stigma in the local languages; through assessment of the extent to which people at the community level used similar or different words to understand and describe stigma; and through an analysis of print media. MUCHS researchers also explored HIV and AIDS-related stigma and discrimination within a health care training setting.
- ▶ **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 through workshops and in-depth interviews.

## Analysis

All interviews were recorded on tape, transcribed, and translated into English. Manual thematic analysis was conducted, and key domains for analysis identified and data coded. N4 software was then used to systematically process and analyze the qualitative data. The quantitative data was entered, cleaned, and analyzed using SPSS and STATA statistical packages.

### 2.1.2 The Vietnam study<sup>4</sup>

#### Partners

The Institute for Social Development Studies (ISDS), based in Hanoi, conducted the research with technical support from ICRW.

<sup>4</sup> See Hong et al. 2004 for a full report on this study.

## Objectives

The objectives of the Vietnam study were to:

- (1) document the experiences of people living with HIV and AIDS;
- (2) explore how HIV and AIDS-related stigma interacts with other stigmas; and
- (3) investigate the role of gender in the causes and consequences of stigma.

## Methods and sampling

The study was conducted in two Vietnamese cities, both relatively badly affected by the epidemic: Hai Phong in the north of the country, and Can Tho in the south. One ward was selected for each city. Due to the sensitivity of the topic, a qualitative approach was deemed most appropriate. The primary methods used to collect data were in-depth interview and focus group discussions. Other methods included observation, photography, and the use of participatory techniques such as matrix mapping and brainstorming. Secondary sources were also consulted widely. Additional information was obtained from key informants who were members of the project's Leadership Advisory Group.

In each research site, the study sample consisted of people living with HIV and AIDS, their family members, and people living in their communities. In selecting participants living with HIV and AIDS, attention was given to whether they were likely to have acquired their infection through injection drug use, involvement in sex work, or by other means. In each site, the research sample included:

- (1) Fifteen people living with HIV and AIDS who participated in in-depth interviews;
- (2) Fifteen male and female family members of people living with HIV and AIDS who participated in in-depth interviews;
- (3) Sixty-four community members from each ward who participated in FGDs; and

- (4) Thirty-two local leaders from each ward who participated in FGDs.

Local leaders in each ward also participated in in-depth interviews. Additional key informant interviews were conducted with local health workers, teachers, and other members of the community.

## Data processing and analysis

Following data collection, all taped interviews and FGDs were transcribed and around 20 percent translated into English for review by ICRW. The ISDS team was trained in the use of NVIVO 2.0 qualitative data management and analysis software. Key domains for analysis were identified, data was coded, and a codebook and preliminary analytical framework developed. Manual thematic analysis was also conducted.

### 2.1.3 The anti-stigma toolkit<sup>5</sup>

During the course of the Africa stigma research, it became clear that few tools are available to assist NGOs and communities in tackling stigma. Based on the research findings and the country teams, ICRW and the AED/CHANGE Project, with the active participation of more than 50 NGOs in Ethiopia, Tanzania, and Zambia, designed a toolkit to help people at all levels understand stigma—what it means, why it is an important issue, its root causes—and develop strategies to challenge stigma and discrimination. Section 4.2 contains more detailed information on how the toolkit was developed and highlights of the content.

## 2.2 Important elements of context

This report synthesizes research across four countries with different social, economic, political, historical, and geographic contexts, each with a different experience of the HIV/AIDS epidemic. It finds that despite sometimes dramatic variations, HIV and AIDS-related stigma and discrimination is remarkably consistent. What we find, looking across contexts, are

<sup>5</sup> The Africa Toolkit can be found at: <http://www.changeproject.org/technical/hivaids/stigma/StigmaToolkit.pdf>.

commonalities in what *causes* stigma, the *forms* in which stigma is expressed, and the *consequences* of stigma—each of which will be described in detail later in this document. Variations that stem from differences in language, culture, and epidemic history are largely of nuance and degree rather than substance. This section briefly highlights some of the differences in context that influence HIV and AIDS-related stigma and discrimination. Although there are important differences among the three African countries,<sup>6</sup> the emphasis will be on comparing the African sites as a whole with Vietnam.

### 2.2.1 The HIV/AIDS pandemic

The HIV/AIDS pandemic is increasingly thought of as not one, but many different localized epidemics. The most important differences between the African and Vietnamese settings in terms of HIV and AIDS-related stigma stem from the different types of epidemic they are experiencing. Although there are differences among the three African countries in terms of prevalence (see Table 1 below), all three countries are experiencing a generalized HIV epidemic. HIV and AIDS in these countries are no longer confined to specific risk groups, but are being experienced by the population as a whole. As a consequence, transmission in all three countries is primarily through heterosexual penetrative

intercourse. In addition, prevalence rates in all three countries are high, although Zambia's overall prevalence rate of over 16 percent is significantly higher than Tanzania's at 8.8 percent or Ethiopia's at 4.4 percent. The impact on households of the higher prevalence rate combined with deep poverty is evident in the Zambian data, where fatigue and poverty fuel stigma.

Vietnam, on the other hand, is still experiencing what is known as a "concentrated" epidemic: HIV infections occur primarily among a few select population groups, the most important of which is injection drug users (IDU), who bear nearly 60 percent of all HIV infections.<sup>7</sup> Sex workers (3.1 percent), TB patients (4.4 percent), and people attending clinics for sexually transmitted infections (1.8 percent) are also experiencing relatively high prevalence rates, and youth are heavily affected (10 percent of those living with HIV and AIDS are between 10 and 19 years old, and 55 percent are between 20 and 29 years old). The overall prevalence rate in Vietnam, however, remains relatively low at around 0.4 percent.

These differences result in important variations in the number of infections found in women. In sub-Saharan Africa generally, and in the three countries studied, women experience more than

**Table 1. Comparing Statistics on the HIV/AIDS Pandemic\***

Country	Number of Adults (15-49) Living with HIV (End 2003)	Prevalence Rate (%)	Women (15-49) (End 2003)
Vietnam	200,000	0.4	65,000
Ethiopia	1,200,000	4.4	770,000
Tanzania	1,400,000	8.8	840,000
Zambia	880,000	16.5	470,000

\*Data from UNAIDS 2004. Report on the Global AIDS Epidemic. Geneva, Switzerland.

<sup>6</sup> See Nyblade et al. 2003 for an exploration of these differences.

<sup>7</sup> Interestingly, in their recent Epidemiological Update on Vietnam, UNAIDS reports that, despite the high prevalence of HIV among IDU, it is likely that up to 80 percent or more of HIV infections are sexually transmitted (UNAIDS 2004b).

50 percent of all HIV infections, whereas in Vietnam women make up around one-third of those living with HIV.

The presence of stigma is perhaps less surprising in a country like Vietnam where the epidemic is concentrated among those already stigmatized and marginalized (injection drug users and sex workers). Yet as these studies clearly indicate, whether the epidemic is contained within subgroups or has spread more broadly to the general population, there is little difference in the ways stigma is expressed. As will be discussed in detail in the following sections, differences in the type of epidemic experienced in fact mask important underlying commonalities that operate to ensure that stigma and discrimination persists.

One key feature distinguishing the context in Vietnam from the other three countries is the way in which HIV and AIDS have so strongly been linked, in policy and programs, with illegal drug use and prostitution—both of which fall under the general rubric of “social evils.” In 2000, the government of Vietnam merged its National AIDS Committee with its committees on the control of illicit drugs and prostitution to create the National Committee for AIDS, Drugs and Prostitution. This committee included members from the National Drug Standing Bureau and the Department for Social Evil Prevention. Although this structure changed in 2003, the act of combining these three social issues under one

program umbrella firmly established the link between HIV and social evils in the public imagination. Despite the absence of this very specific policy and program link in the African countries, however, the association between HIV and AIDS and behaviors deemed socially deviant is nevertheless strong, as discussed in Section 3.1.2.

A further important difference among all four countries relates to variations in the duration of the epidemic. In Ethiopia and Vietnam, for example, where AIDS has only relatively recently emerged as a problem, lack of in-depth knowledge about HIV and its transmission was a greater driver of stigma than in Zambia. However, lack of in-depth knowledge about HIV transmission was nevertheless a central cause of stigma in Zambia and Tanzania as well. (This is discussed further in Section 3.1.1.)

## 2.2.2 Economic situation: the relationship between poverty and stigma

Although comparison of the data in Table 2 is imperfect due to the different years in which data were collected, these figures still indicate some degree of variation among all four research countries in terms of poverty. All four countries can be characterized as poor, with Zambia clearly the poorest, where not surprisingly, poverty emerged most clearly as a factor precipitating and exacerbating stigma (Bond, Chilikwela et al. 2003). Across all four country settings, it was acknowledged that poverty plays a role in driving people (especially women)

**Table 2: Comparative Statistics on Poverty<sup>2</sup>**

Country	% Pop. Below \$1/day	Survey Year	% Pop. Below Nat'l Poverty Line	Survey Year	Gini Index*	Survey Year
Ethiopia	26.3	1999-2000	45.0	1999-2000	30.0	2000
Tanzania	19.9	1993	38.7	2000-2001	38.2	1993
Zambia	63.7	1998	83.1	1998	52.6	1998
Vietnam	17.7	1998	57.2	1993	36.1	1998

<sup>2</sup> Data from World Development Report 2005: A Better Investment Climate for Everyone. The World Bank, Washington, D.C.

\*The Gini Index is a measure of inequality. The closer the number is to **0**, the more equally distributed income is among individuals or households. The closer the number is to **100**, the more unequal this distribution is.

to engage in behaviors (such as sex work) that make them vulnerable to infection. Generally, the rich were more likely to be stigmatized than the poor because it was felt that they deserved their fate for indulging themselves in sinful and/or pleasurable behaviors “just for fun.” However, this tendency to stigmatize the rich was mitigated by the fact that the wealthy could more easily hide their HIV-positive status from the general public. In addition, the poor were more likely to experience stigma at home due to the greater strain that caring for someone with HIV and AIDS imposes on a poor household economy than on a rich one.

In Vietnam, poverty emerged less as a specific driver of stigma than in the other three countries. This might be a reflection of the fact that the HIV epidemic is less pervasive there as well as of the country’s economic structure. In Vietnam, families may have one or at most two members living with HIV, whereas in the three African countries many families will have multiple members affected—if not within their immediate household, then within their extended families. The costs of caring for even one person who is sick or dying with AIDS can be devastating for any poor family, but when these costs are multiplied, the weight of the cost burden can become unbearable—driving some families to stigmatize, even neglect, their members living with HIV and AIDS.

### **2.2.3 The importance of religion**

A further important distinction between the three African countries and Vietnam relates to the relative importance of religion. All three African countries are characterized by a profusion of religious orders and sects, most relating either to Christianity or Islam, nearly all of which

are layered over pre-existing (traditional) belief systems. Vietnam, on the other hand, is a predominantly secular society, grounded in Confucianism in combination in recent decades with a strong commitment to socialist doctrine. In all four countries, the living retain a strong connection to the dead through the respect given to ancestors. The forms which this ancestor veneration takes vary substantially from one country to the next (in some, such as Vietnam, it is much more formalized than in others), but this continuity also has implications for HIV and AIDS-related stigma experienced by families of people living with HIV, as will be discussed in Section 3.3.2.

This background section has briefly described the four studies and discussed some of the contextual differences among the four study countries. It is clear that there are variations in the nature of the epidemic, the response to it by policymakers, and the socio-cultural environments in which stigma occurs. Clearly, any response to HIV and AIDS-related stigma and discrimination will have to account for the specific contextual elements in each country. However, despite these important variations in context, the fundamentals of stigma are remarkably similar in all four countries. The differences in context contribute to differences in expression and degree, rather than core substance. The findings discussed in this document suggest that it is possible to develop anti-stigma interventions that have a common core, but which can be adapted fairly readily to different social, economic and health services contexts. The project teams have, in fact, taken a first step in this endeavor with the development of the two anti-stigma toolkits.

The following section will provide greater detail, synthesizing the main findings of the four country studies.

## 3

## Findings

### 3.1 The root causes of stigma: knowledge and morality

#### 3.1.1 The role of knowledge about HIV and AIDS and fear

This section explores the root causes of stigma related to knowledge or understanding of HIV and fear of HIV transmission through routine, noninvasive daily interactions (casual contact) with those living with HIV and AIDS, and how these lead to stigma. The fundamental similarities across the four countries in all aspects of fear and knowledge and their relationship to stigma are striking. Only nuanced differences emerge, for example in the particular form of casual transmission that is most commonly feared, or the particular places where that fear manifests itself.

#### What people fear

Across all four countries, fear that HIV could be transmitted through ordinary, daily interactions with people living with HIV and AIDS that involve *no* exchange of body fluids was common. Examples include contact with an HIV-positive person through simple touch (shaking hands, kiss on the cheek, sitting next to); eating food prepared by or which may have come in contact with those living with HIV and AIDS; breathing infected air; or using objects that someone living with HIV and AIDS had touched (e.g. clothing, bedding, or eating utensils). These quotes from Ethiopia, Zambia, and Vietnam are representative of the fears expressed across all the countries.

*It [HIV] might be transmitted through breathing, we do not know. So being careful is necessary: avoiding eating food coming from the patient's home, not sharing clothes*

*and not drinking with the glass that the patient used. This is what I think. (man, Ethiopia)*

*People are also afraid whenever he [the person living with HIV] cooks or cleans the rice.... During meals, they also fear sharing things. The family is so fearful. Of course, the family does love him, but... (wife of a person living with HIV and AIDS [PLHA],<sup>8</sup> Vietnam)*

*Maybe when I eat with him, I will swallow a virus and contract the HIV/AIDS. (man, Zambia)*

#### How fear causes stigma

Fear of and preoccupation with transmission through everyday casual contact leads directly to stigma in the form of isolation of persons living with HIV and AIDS in all aspects of daily life. It occurs everywhere, from within the home, to social gathering places in the neighborhood, to the market place, health facilities and even sometimes in places of worship. These quotes illustrate how fear of a wide range of casual transmission situations leads directly to stigma.

*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. (man, Zambia)*

*Some people in this community believe that HIV/AIDS transmits through kissing, shaking hands, sleeping together [in the same room],*

<sup>8</sup> Though we appreciate the importance of not referring to persons living with HIV and AIDS as acronyms, we do use PLHA when citing direct quotes as a means to shorten the text and ease reading.



*and eating together with an infected person. Due to this they isolate the person from the community. For example, if they see him passing the same way they are passing, they change their way not to kiss and shake hands with him... because they are assuming that it is transmitted through breath, shaking hands, eating together with an infected person. (woman, Ethiopia)*

*For self-prevention of the disease, I think I should keep far from PLHA because those persons [can infect me]. As we know for*

*prevention of disease, to keep away is best. (woman, Vietnam)*

### **Preoccupation with unlikely modes of transmission**

The common fear across all countries of modes of casual transmission that carry extremely low, if any risk, is striking. In particular, many fear even the most peripheral contact with blood (e.g., left on nail clippers or hair cutting scissors or through mosquitoes), and other nonsexual body fluid (saliva, sweat). Some of the most common fears expressed across countries in relation to this preoccupation are captured by the following statements:

#### **Box 2: Basic Facts About HIV Transmission**

AIDS (Acquired Immune Deficiency Syndrome) is caused by a virus, HIV (Human Immunodeficiency Virus). HIV is *not* transmitted easily. In fact, HIV is a fragile organism that is easily killed on contact with air and water. HIV can only be transmitted directly by having sexual intercourse with an infected partner without using a barrier, such as a condom; through the direct exchange of blood or body fluids; or from an infected mother to her child during pregnancy, delivery or breast milk ([www.who.int/hiv/about/hiv/en/](http://www.who.int/hiv/about/hiv/en/)). Unlike some bacteria and fungi, HIV is unable to reproduce outside its living host. Therefore, it does not spread or maintain infectiousness outside its host ([www.cdc.gov/hiv/pubs/facts/transmission.htm](http://www.cdc.gov/hiv/pubs/facts/transmission.htm)).

In this research, we found that the mode of transmission described above as “through the direct exchange of blood or body fluids”—commonly referred to in Vietnam as “through blood”—is the most commonly misunderstood mode of transmission in Vietnam. According to the U.S. Centers for Disease Control and Prevention (CDC), what “through blood” actually means is that HIV can be transmitted “by sharing needles and/or syringes (primarily for drug injection) with someone who is infected, or, less commonly (and now very rarely in countries where blood is screened for HIV antibodies), through transfusions of infected blood or blood clotting factors.” CDC goes on to explain, “Some people fear that HIV might be transmitted in other ways; however, no scientific evidence to support any of these fears has been found. If HIV were being transmitted through other routes (such as through air, water, or insects), the pattern of reported AIDS cases would be much different from what has been observed. For example, if mosquitoes could transmit HIV infection, many more young children and preadolescents would have been diagnosed with AIDS” (see [www.cdc.gov/hiv/pubs/facts/transmission.htm](http://www.cdc.gov/hiv/pubs/facts/transmission.htm)).

*... [HIV] is transmitted through blood and unsafe sexual relationships only... but in case we are grazed, it can be transmitted through blood—even if it is a small scratch only.... Cutting hair may also cause the disease. For example, if we hold the scissors that makes our skin grazed, another person who holds it later could be infected, too. (woman, Vietnam)*

*I cook buns and fry fish and groundnuts for sale; 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?”... People say: “She may have dropped sweat there; she may have scratched herself then touched the fish.” People will not buy the fish... (woman with HIV, Tanzania)*

*I fear people living with HIV and AIDS because AIDS might be transmitted through clothes and shaking hands. ... We fear it might be transmitted to us through touching their clothes and through sweat. (man, Ethiopia)*

*They know the virus lives in the blood. Immediately they see blood, they think of the virus... this is the type of contact they fear most. (NGO manager, Zambia)*

### Knowing, but still doubting

This fear of and preoccupation with contracting HIV through impossible or highly unlikely routes persists across all four countries despite high levels of knowledge about how HIV is transmitted. Data from all four countries (Bond, Chilikwela et al. 2003; Banteyerga, Kidanu et al. 2004; Hong, Van Anh et al. 2004; Mbwambo, Kilonzo et al. 2004) show that respondents know, or at least can easily recite, the three correct modes of HIV transmission (sex, blood, and mother-to-child). However, correct knowledge does sometimes coexist with incorrect beliefs about transmission, and there is often a lack of confidence about how HIV is *not* transmitted. The doubts and concerns that exist despite “knowing” that HIV is only transmitted in three ways is described by a health worker in Vietnam and an elder in Tanzania:

*I am a health professional; I know that HIV is transmitted only in three main ways. But when I come into contact with them [people living with HIV and AIDS] I still worry and feel nervous. ... In my case it is my duty, my responsibility to work with them, to go to them. But in fact I am fearful.*  
(health provider, Vietnam)

*Even though it is said that HIV is not transmitted through eating, people will still avoid you [if you are infected].* (Elder, Tanzania)

### Persistent focus on casual transmission

The data suggests that the persistence of doubts about how HIV is transmitted despite knowing otherwise and the fixation on the least likely modes of transmission could be the result of several interacting factors.

#### Lack of specific, in-depth information about HIV transmission

The first is the narrowness and lack of depth<sup>9</sup> and specificity in much HIV and AIDS information.

Standard HIV and AIDS messages often focus solely on how HIV is transmitted, that it has no cure, and that it kills. Such messages tend to convey the incorrect impression that HIV is highly infectious. Rarely do HIV and AIDS messages focus on explaining how HIV is *not* transmitted, the relative infectiousness of HIV, and the fact that HIV is *not* easily viable outside the human body. These messages, therefore, allow fears of casual transmission to go unchallenged and to persist. By not specifically addressing the risk of HIV transmission through routes that are of common concern in people’s daily lives (e.g., noninvasive contact with blood, sweat, saliva, and mosquitoes), the possibility is left open that these are indeed risk situations to avoid. That these fears do exist and lead directly to stigma is amply demonstrated in the data from all four countries.

Ambiguous or vague messages about transmission also can perpetuate the incorrect assumption that daily interactions with people living with HIV and AIDS pose a serious risk of infection. This is particularly the case for the blood mode of transmission (Bond, Chilikwela et al. 2003; Hong, Van Anh et al. 2004; Mbwambo, Kilonzo et al. 2004). Because of the lack of clarity in standard messages about how much, and through what means, blood poses a transmission risk, people do not have the information they need to accurately assess the transmission risk of coming into contact with blood from an HIV-positive person by touching an object or brushing up against someone living with HIV or AIDS (e.g., in a road accident), versus through a blood transfusion or dirty needle. Lacking this clarity, many people remain preoccupied with and fearful about common situations where transmission risk is minimal. The lack of specificity and clarity in messages about HIV transmission, in particular with relation to blood, and how this fuels stigma is brought out clearly in all countries through discussions of hypothetical daily

<sup>9</sup> While we focus here specifically on the issue of knowledge related to HIV transmission, the data from the African countries show how a lack of in-depth knowledge around living with HIV, for example the longevity of a person with HIV or the difference between HIV and AIDS, leads to the belief that HIV equals immediate disability and death, and that people living with HIV and AIDS are not productive members of society, but a burden. These attitudes are reflected in much of the language used to label and describe those living with HIV and AIDS.

interactions with people living with HIV and AIDS. Typical concerns expressed by study participants included the following:

*What if I'm sitting on a bus next to someone with HIV or AIDS and the bus crashes, that person bleeds and I'm cut, and some of his or her blood gets on my open wound?*

*What if an HIV-positive person cooking food cuts themselves and blood drips into the food, which I then eat?*

*What if an HIV-positive person drips sweat into the food they are handling or I use a bed sheet or article of clothing a person with HIV and AIDS has sweated on?*

*What if a fingernail clipper was used by a person with HIV and AIDS, they cut themselves with it, some dried blood remains and then I use it and cut myself in the process?*

*What if the person has diarrhea and when washing the messed clothes you have a cut and are not wearing your gloves for protection, you may [contract HIV] as well.*

The following quote captures how people's doubts about HIV transmission can have an impact on daily life:

*They say eggs transmit the infection. They say do not eat eggs since they can be infected. ... Hens are everywhere in town, hotel, bars, restaurants. The people working there use condom and throw it in the open field. Hens eat this. If the condom has the virus the hens get infected because they swallow it with this thing [sperm]. The virus goes to the egg, and if we eat raw eggs we get infected. So people say do not eat raw eggs. (man, Ethiopia)*

Given the narrow and often incomplete or ambiguous knowledge about how HIV is, or is not, transmitted, it is not surprising that the common conclusion to a *what if* scenario is that it could potentially pose a significant risk of transmission and therefore should be avoided.

The data from all countries illustrates the highly complex thinking process that occurs as individuals try to make sense of the information they have received as applied to the reality of their daily lives. It also shows how having only partial information can lead to incorrect conclusions about the risk posed by casual transmission. This, in turn, may lead to actions that, while perceived simply as preventive, in fact result in stigmatizing behaviors, such as minimizing or restricting contact with people living with HIV and AIDS. For example, many people refuse to sit next to infected people on a bus, eat food they have cooked, buy produce from them, or share objects with them:

*If you are sitting in the bus and sometimes you are facing somebody [who] looks like they have symptoms and she is coughing profusely, you just find everybody will be turning on the other side. (home-based care coordinator, Zambia)*

Adding to the confusion, doubt, and fear over whether, and how much, daily activities pose a risk for HIV transmission is the widespread and well-established knowledge about how other viral and bacterial diseases are transmitted, particularly those commonly associated with HIV (like tuberculosis and diarrhea), and other diseases that have a transmission cycle that includes blood and biting insects, in particular malaria (Bond, Chilikwela et al. 2003; Hong, Van Anh et al. 2004). Given this knowledge, doubt and fear creeps in that HIV might be transmitted this way too. Knowing that TB is airborne, diarrhea contracted through infected water, contaminated food, and infected body fluids or objects, and malaria through mosquitoes, people often reason that perhaps HIV could be transmitted these ways too. Without a greater depth of knowledge about how HIV is, and is not, transmitted, and direct explanations from trustworthy sources as to why HIV cannot be transmitted in the same way as TB, diarrhea, or malaria, doubt will remain that it can be. Given the consequences of contracting HIV, as long as even the slightest doubt remains about the possibility of transmission through everyday contact, the

choice will be made to, where possible, avoid contact with people with HIV.

### **Fear-based public messaging**

Another factor that adds to the fear and desire to avoid any situation that might pose a potential transmission risk is the legacy of fear and panic created by fear-based messages about HIV,<sup>10</sup> coupled with sensationalized reporting around HIV. Fear-based messages in health campaigns focused heavily not only on death as the outcome of HIV, but also on the depiction of a painful, disfiguring, and sometimes shameful death (through linking HIV to socially unacceptable behaviors).<sup>11</sup> Hong et al. (2004) write about the experience in Vietnam as follows: “Many posters use highly emotive symbols such as human skulls, bleeding syringes, and coffins, or they contrast images of sick and dying drug users with images of robust, healthy people.” These kinds of messages heighten the anxiety and magnify the fear of contracting HIV. As put by a health worker in Zambia, “They just make people scared.” This fear fuels stigma in the form of isolation of people living with HIV and AIDS, as explained by a female respondent in Ethiopia:

*The reason people isolate a person living with HIV/AIDS is because they fear HIV/AIDS. The reason they fear HIV/AIDS is because they hear from different mass medias, i.e. radio and TV, how horrible this disease is and how it is widespread in the country.*

The focus, both in public health campaigns and the media, on negative images of sick, dying, and disfigured persons; the sensationalization of alleged cases of vindictive and purposeful infection of others by people living with HIV and AIDS (for example by injecting their blood into others or having premeditated unprotected sex); and lack of positive images of the more prevalent reality of people with HIV and AIDS who are productive and responsible members of society ratchets up the fear and panic of



*As an example of fear-based messaging, the press reported that this boy was deliberately injected with blood contaminated with HIV by someone seeking revenge against his father.*

contracting HIV, hence creating stigma toward those living with HIV and AIDS. As a woman in Ethiopia explained:

*When I watch TV and listen to the radio HIV/AIDS program presented in the form of drama, the message of the drama scares me and makes me cry. ... In the drama they show how the disease makes people suffer and change their physical appearance and look. It disfigures the face of the patient, changes the color from dark to pale. This makes me worry much.*

In addition to perpetuating stigma, the creation of this fear has public health impacts. For example, people may avoid getting tested for HIV. Mbwambo et al. (2004) describe the impact on testing as follows: “Respondents also discussed how fear of testing is related to images people have of a grossly disfiguring disease as shown on billboards and that a positive finding of a test implies a sentence of death.” People may also believe that only sick-looking people have HIV, and so deny their own potential risks and any need for behavior change. A woman in Ethiopia explained how images of thin, sick people with HIV and AIDS create fear and stigma, as well as feeding the misconception that only sick-looking people have HIV.

<sup>10</sup> Fear-based messages were common early in the pandemic in Africa, and until very recently in Vietnam. See Hong et al. 2004 for more detail on the content of fear-based messages in Vietnam.

<sup>11</sup> See Section 3.1.2 for more on the moral dimensions and linking of HIV to “immoral behaviors.”

*Advertisements and dramas [that show only thin people with AIDS] encourage people to fear HIV and AIDS and people with HIV and AIDS very much. Moreover, they make people think that a healthy-looking person doesn't have HIV and they isolate thin people.*

### **Evolving knowledge on HIV and AIDS**

Adding additional doubt to the mix is the relative newness of the HIV epidemic and the constantly evolving, sometimes contradictory, scientific and medical knowledge about HIV and AIDS (Bond, Chilikwela et al. 2003). Because knowledge continues to grow on all aspects of HIV, including transmission, people begin (or continue) to doubt the validity of existing information, causing fear that current information about transmission might be wrong.

The prevalence of “what if” questions, the preoccupation with impossible or highly unlikely modes of transmission, and the continued fear of casual transmission across all countries also indicate that individuals are not receiving information in an interactive format that allows people to think through the information received, discuss it, and then raise questions with an informed, trusted moderator to provide answers.

### **3.1.2 The role of values, norms, and moral judgment**

The moral dimensions of stigma are well known and indeed can be traced back to the original meaning of the word itself, which according to Goffman relates to “bodily signs designated to



expose something unusual and bad about the moral status of the signifier” (Goffman 1963). Like the fears associated with HIV transmission discussed in the previous section, assumptions made about the moral integrity of people living with AIDS were a central cause of stigma in all four countries, and these assumptions underpin the tendency to blame people for their HIV infection—as well as the shame felt at some stage almost universally by those living with HIV and AIDS and those associated with them.

The tendency to link HIV and morality might be related to the fact that affliction is often perceived as an outward manifestation of a moral transgression. In some Asian cultures, these perceptions might be couched in terms of *karma*.<sup>12</sup> In a number of African societies, specific illnesses or sets of symptoms are associated with having broken one or more social prohibitions. Among the Tswana people, for example, the term *meila* refers to transgression against any of a number of taboos surrounding sexual relations and childbirth (Staugard 1985), and many sexually transmitted infections are attributed to *meila*. Elsewhere, including the Judeo-Christian traditions of North America and Europe, it is not uncommon for people to believe that illness is a punishment for one’s sins.

Whatever its roots, the tendency to associate illness with moral impropriety is a central contributing factor to HIV and AIDS-related stigma. This stigma is exacerbated by the seriousness of the illness, its mysterious nature, and its association with behaviors that are either illegal or socially sensitive (e.g., sex, prostitution, and drug use). Also relevant is the perception that HIV infection is the product of personal choice: that one *chooses* to engage in “bad” behaviors that put one at risk and so it is “one’s own fault” if HIV infection ensues. A woman in Ethiopia, for example, explained:

*Those who go out of God's permission will be infected. I always advise my children to be loyal to God and respect his rules. Thus, I*

<sup>12</sup> Karma can perhaps most simply be thought of as the law of cause and effect. The principle is similar to that expressed by the Christian verse, “As ye sow, so shall ye reap.” The word karma means “action” and is used as shorthand for the idea that every action causes a reaction in the future. Actions that are in harmony with moral precepts will bring positive results back to you, whereas actions that contravene these precepts will bring you suffering.

*won't mind if they refuse to be loyal to God and die [of AIDS].*

All of these elements have strong resonance with the moral dogmas of many religious texts as well as with the form of socialism practiced in Vietnam. In Zambia, for example, most respondents identified “immorality” as the main factor influencing the spread of HIV and AIDS. As one religious leader in Lusaka put it, “Those patients are promiscuous... careless with themselves. God is punishing them for disobedience... because the diseases are not traditional in nature and those affected are examples of what God can do to those who disobey His commandments....” Similarly, the following statement was made in Tanzania: “...AIDS is like Sodom and Gomorrah—an abomination of God... it is chastisement. In the Bible it says that ‘I will not destroy with water or fire.’ What a person sows so shall he reap.” In Vietnam the same types of sentiments were expressed, but couched in different terms. Rather than the explicit religious references, the Vietnamese refer to people with HIV as having contracted the virus through a lack of self-discipline—through “indulging in play” and engaging in “social evils.” Lack of seriousness, discipline, and personal integrity contravenes many of the core tenets of Vietnamese society, which stem ultimately from Confucianism. Notably similar findings have been identified elsewhere, for example in Thailand (Songwathana and Manderson 2001).

This section explores the intersection between HIV and AIDS-related stigma and the values and norms that frame any moral community, but in particular those of our study sites. Three common elements are discussed: (1) the ways in which HIV and AIDS-related stigma functions to sharpen the boundaries of the moral community—creating a clear division between “us” (the presumably uninfected), and “them” (those known or presumed to be living with HIV and AIDS); (2) the tendency in all sites for members of the wider community to assign degrees of “guilt” or “innocence” to HIV-positive people according to assumptions about how that

person acquired his or her infection; and (3) the role of gender in these processes.

### **Creating a divide between “us” and “them”**

Across all the sites, HIV and AIDS-related stigma has become a mechanism for sharpening the boundaries of the “moral community,” whether religious, as in all three African sites, or socialist/Confucian as in Vietnam. In other words, stigma reinforces previously defined boundaries between “us” (the normal/righteous/upstanding citizens) and “them” (the deviant/bad/“fallen” ones). The fact that one has become infected with HIV is used to distance that person from the mainstream community, to set him or her apart, marked out as having transgressed or sinned against god and/or society. This mark (or literally, “stigma”) is a cause for opprobrium in and of itself—but all the more so because of the perception that he or she has become infected by *choosing* to do things (such as inject drugs or have unsanctioned sex) that he or she *knows* are wrong. Herek and Glunt (1988) discuss this phenomenon in relation to an earlier phase of the HIV epidemic in the United States and note that the public health language serves to underscore this boundary-making: “the general public” is distinguished from “risk group”—suggesting that gay men and IDU are not members of the general public. It is important to note that this type of distinction persists today, where we are seeing the return to a focus on “core transmitters” and “high risk groups” in the U.S. public health system. This boundary-making serves at least two purposes: it enables the (apparently) uninfected to reinforce their notions of themselves as being morally right and upstanding citizens, while also allowing this group to deny its own level of risk, thereby enabling them to believe they have no need to contemplate any changes to their own behavior.

In Vietnam this separation can be quite explicit, as the following quotes (both from Hong, Van Anh et al. 2004) indicate. Many people disguise their contempt for people living with HIV and AIDS by expressing their sentiments as “legitimate” concerns about prevention. This 65-year-

old father of an HIV-positive man believes the government should put all those living with HIV on an island to live and work together. He explained further that:

*The government should not let PLHA wander in the community and in the society. They should be split off. I say this not because I hate them, but because I am thinking of the protection of the community. (father of PLHA, Vietnam)*

In another city, Hai Phong, a 50-year-old woman participating in a focus group discussion expressed a similar opinion:

*... the government should create a separate area in order to limit them [PLHA].... If there is no separate place and we let them [intermingle] like now, people will be afraid.*

The presence of HIV also enhances pre-existing stigmas and serves to retrench social values and norms about correct, normal, or appropriate behavior. In Vietnam this takes the form of a discourse of social evils. In the African settings it tended to be couched in religious terms—especially reinforcing the pre-existing stigma against sex workers and youth. This issue is discussed further below.

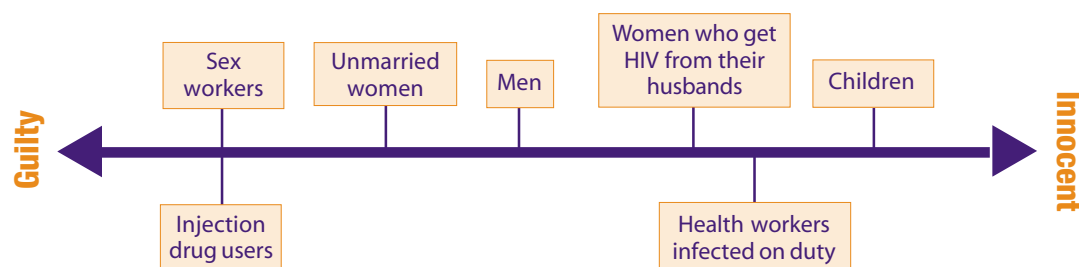
### **The continuum between “innocence” and “guilt”**

Because of the clear associations that exist in peoples’ minds between HIV infection and morally incorrect behaviors, and as a way to distance oneself from any possibility of HIV risk, the first question invariably in peoples’ minds when they discover someone is living with HIV is: *How did he/she get it?* Often the asker will answer the question simply through assumptions made about the person’s character or known behaviors. Because of variations in the nature of the epidemic among the four countries, the most common answer to this question differed somewhat across sites. In the three African countries, for example, it was generally assumed

that the person in question became infected with HIV through sex—more specifically through inappropriate, “immoral” or “disorderly”<sup>13</sup> sex. In Vietnam, if the person in question was a man, especially a young man, it was generally assumed that he became infected through injection drug use, sex with prostitutes, or generally “indulging in play.” Clear distinctions were made in all sites between those who became (or were presumed to have become) infected through such “improper” behaviors, and those who were deemed “innocent victims”—such as sexually faithful married women (or men) who became infected because of their spouse’s philandering; health care workers or police infected in the course of their work; or children infected through vertical transmission. Thus, in all sites there exists in people’s minds a kind of continuum from presumed “guilt” to presumed “innocence.” Although all people with HIV experience some degree of stigmatization, where one falls along this continuum will determine, to a significant extent, the type and degree of stigmatization received from one’s family and the wider community. The parallels across the sites in how this continuum is arranged are striking with only a few important differences being, for example, the prominence of injection drug users in Vietnam and the relative importance of youth as a “guilty” group in Africa.

Box 3 depicts this continuum in schematic form—combining impressions and data from the African and Vietnamese sites. This schematic broadly generalizes a complex picture into a few categories plotted in a very simplistic and linear way. In real life, the specific placement of any individual in any single circumstance will vary considerably, sometimes from one person to the next. The category broadly labeled “women who get HIV from their husbands” is a good example. The extent to which such a woman is considered more “guilty” or “innocent” will depend on a range of factors. For example, is she considered by the community to be a “proper woman”? If so,

<sup>13</sup> Bond et al. 2003:34 discuss this notion of “disorderly” sex, citing Mogenson 1995, 1997.

**Box 3: Schematic of “Innocence-to-Guilt” Continuum**

she is likely to be deemed “innocent,” an unwitting victim of her husband’s bad behavior. However, if such a woman has been in conflict with any of her neighbors or if for some other reason the community wants to cast her out, then people will find reason to question her moral integrity and guilt will be imputed.

These “cognitive continua” were illustrated in a number of ways, as the following quotes indicate:

*In the case of women who unfortunately get infected, we should give them support and educate them so that they can avoid transmitting to others. Regarding the case of drug injectors, the damage is already done and they cannot be educated. We should definitely put them in a separate place because we cannot educate those people. The other group—they deserve our pity and we should protect them* (participant in FGD of women over 50 years old, Vietnam).

*The unfaithful, like in marriage, deserve it while the faithful ones do not deserve it.*  
(TB patient, Zambia)

The continuum also indicates the ways in which HIV and AIDS-related stigma interacts with pre-existing stigmas; in addition to creating stigma where none previously existed, HIV and AIDS create *double* stigma—the pre-existing stigma associated with an unapproved behavior (such as injection drug use or “immoral” sex), in combination with the stigma of living with HIV. In Vietnam, injection drug use and prostitution

are widely regarded as social evils, an association entrenched in the minds of the public as well as in legislation and policy (see Hong, Van Anh et al. 2004). Because HIV often is associated with these pre-existing stigmatized groups, HIV itself has started to be referred to as a social evil. This linkage between HIV, drug use/sex work, and social evils therefore not only affects those who do engage in these behaviors, but all people living with HIV, serving to magnify HIV and AIDS-related stigma and the misery it creates. A parallel example from the African settings relates to the close association made between HIV and AIDS and promiscuity, as can be seen in the following remark of a woman in Ethiopia:

*The community believes that people get infected [with HIV] due to their deviant behaviors when they are having sexual contact with different partners. They think that a person who is infected is a promiscuous person.*

Given the close associations between HIV and moral impropriety, the finding in all sites that the harshest stigma is reserved for those expected to uphold moral laws and the moral fabric of society should not be surprising. In all sites, for example, HIV-positive women tended to be more highly stigmatized than men (this is discussed further in the next section). In Africa, those in the clergy who became infected with HIV were the object of particular opprobrium, while the equivalent in Vietnam was members of the Communist Party. Because these are the social roles specifically designated as moral and



social role models, their “fall from grace” is particularly heavily stigmatized. The following quotes illustrate this phenomenon:

*If let's say the pastor has HIV/AIDS, the respect there goes away. Even the Bible he is holding, people will say it's also contaminated. Whatever he says, people won't listen.*  
(traditional healer, Zambia)

*If you are a Party member, for example, and you go and do an indecent thing and you get infected, the Party should definitely expel you.* (participant in FGD of grassroots organizations, Vietnam)

In addition to serving as a mechanism for inducing and enhancing stigma, the innocence to guilt continuum, like the “us” and “them” boundary strengthening, also creates the possibility of absolving people from guilt if they do become HIV-positive. As reported from Zambia, for example, if a health worker can claim that she or he was infected through work and not sexual behavior, and that he or she is therefore “innocent,” he or she can retain a reputation for being morally upstanding—though even in this case, doubts will likely linger: “Other people will still speculate about how the health worker got infected and make judgments about sexual behavior” (Bond, Chilikwela et al. 2003).

### **Shame, blame, and the role of gender**

A key similarity across all research sites was the role that gender plays in the nexus between HIV-related stigma, moral judgment, shame, and blame. Although this interface was complex, it is clear that women generally bear the strongest brunt of this type of stigma. The reason underlying this seems to be that women in all of these settings are expected to uphold the moral traditions of their societies. HIV is regarded as evidence that they have failed to fulfill this important social function. To phrase the problem otherwise:

Women living with HIV and AIDS (or more often, suspected to be living with HIV and AIDS) are regarded as everything they

should not be—sick and slim when they should be healthy; being cared for when they should be caring for others; sexually deviant when they should be sexually righteous. To be HIV-positive is not to be a proper woman (Bond, Chilikwela et al. 2003).

A fundamental double-standard exists in all study settings, whereby men are generally expected to be reckless, adventuresome and more likely exposed to a whole host of sexually transmitted infections (STIs) (including HIV), and women are expected to be sexually faithful, chaste, and morally upstanding. Again, the specific ways in which these values are expressed may differ from one setting to the next, but the core underlying issues remain startlingly consistent.

In Vietnam, the family is at the center of society. Women, more than men, are expected to put their families first, to support and reinforce the family in all their actions and deeds. Although the socialist ideology of the country promotes and supports equal rights for women in all aspects of social life, both government and society in general continue to embrace traditional Confucian values, including those that apply to gender (Go et al. 2002; JVnet 2004). So, while Vietnamese women are on the one hand encouraged to participate fully in employment, politics, and social life, they are nevertheless expected to prioritize their roles as wives and mothers (Hong 1999; JVnet 2004). A woman engaging in “social evils” such as drug use (which undermines both the reputation and economic well-being of families) or sex work (said to “break the family’s happiness”), therefore, is strongly judged and simply not tolerated; and HIV infection is considered *de facto* evidence of such involvement. This sentiment is expressed in the following quotes:

*People do not hate a drug-addicted man nearly as much as a drug-addicted woman.*  
(participant in FGD of women 18-24 years old, Vietnam)

*To say frankly, if men are still young and they indulge in play and get [HIV] infected, that's the general story of society. If a girl gets this disease, no one would like to get close to her, because it is a problem of her conduct and her morality. It is not tolerated in females compared to males.* (female community counselor, Vietnam)

Although HIV-positive women in general may be more reviled than HIV-positive men in Vietnam, as a whole they are not generally blamed directly for bringing HIV into a family (although they may be in specific instances), as this is often known to have happened through the husband's injection practices.

In Tanzania, Zambia, and Ethiopia, more women than men are living with HIV (UNAIDS 2004a). Findings in all three of these country studies show that women tend to be *both* more heavily stigmatized than men for having “failed as proper woman” *and* blamed more often for “bringing” HIV into a family or marriage. In Ethiopia, for example, although some people are sympathetic to women exposed to HIV for reasons beyond their control, women are nevertheless more likely to be viewed as the source of HIV and blamed (Banteyerga, Kidanu et al. 2004). As a woman explained, “[Women] would be blamed more than men for being promiscuous and contracting the virus.” Similarly, a man (also in Ethiopia) made the following comment:

*A man would receive more respect than a woman because he is a man. And if a man gets infected, it will be said, “He got infected accidentally.” But if the woman gets infected, the gossip about her will be more exaggerated. People say she brought the disease by going out with different men.*

A very similar remark was made by an HIV-positive woman in Zambia, who observed that “the word ‘disgrace’ is used more on women... People say women are the ones who bring

sickness most of the time. They are the ones who start [the illness].”

Whether or not an individual woman is blamed for “bringing” HIV into a home, the impact of HIV and AIDS-related stigma in all study sites was most profound for women, as will be discussed further below.

## 3.2 Expressions and forms of stigma

The forms of stigma documented in each country can be categorized into four broad, loosely defined groups: physical, social, verbal and institutional (see Table 3). While the specific expressions of stigma were numerous and varied within settings, the most frequently experienced forms were similar across countries no matter whether one was in a town in Vietnam, or a rural village in Ethiopia. We focus in this section on the forms of stigma that are directly experienced by people living with HIV themselves, noting where there are particular gender differentials. However, many of the forms of stigma described below are also experienced by people closely associated with those living with HIV and AIDS, like family (including children) and other caregivers.<sup>14</sup> The forms and degree of stigma also change over the course of an infected person's experience with HIV and AIDS. For a detailed discussion of this issue, see Bond et al. (2003).

### 3.2.1 Physical stigma

The forms of physical stigma can be grouped into isolation and violence, with the former being widespread and the latter less common. Physical isolation of people living with HIV and AIDS occurs in all locations, from the home to community gathering or public spaces (like tea shops, markets, sports grounds, buses, places of worship), to within workplaces, schools and hospitals. Common expressions within the home include marking and separating out typically shared objects like eating utensils, clothes, and bed linens and making those with HIV and AIDS sleep in separate quarters and eat alone, highly unusual actions in all these countries where space is limited and eating together is the norm.

<sup>14</sup> Commonly referred to as secondary or courtesy stigma.

**Table 3. Expressions and Forms of Stigma**

Physical	Social	Language/Verbal	Institutional
<p><b>Isolation</b></p> <ul style="list-style-type: none"> <li>▶ Separating sleeping quarters</li> <li>▶ Marking and separating eating utensils</li> <li>▶ Separating clothing and bed linens</li> <li>▶ No longer allowing person to eat meals with family</li> <li>▶ Confinement to certain rooms of house</li> <li>▶ No longer allowing person to participate in housework (e.g. cooking food)</li> <li>▶ Public rejection (refuse to sit next to person on bus, bench, at church, tea shops or in bars)</li> <li>▶ Separation from children</li> <li>▶ Abandonment by family</li> </ul> <p><b>Violence</b></p> <ul style="list-style-type: none"> <li>▶ Beatings</li> <li>▶ Being kicked</li> <li>▶ Throwing stones</li> <li>▶ Arrests</li> </ul>	<p><b>Isolation</b></p> <ul style="list-style-type: none"> <li>▶ Reduction of daily interactions with family and community</li> <li>▶ Exclusion from and shunning at family and community events</li> <li>▶ Loss of social networks</li> <li>▶ Decreased visits from neighbors</li> </ul> <p><b>Voyeurism</b></p> <ul style="list-style-type: none"> <li>▶ Increased visits from neighbors, not out of concern but to mock individual or report back to community</li> </ul> <p><b>Loss of identity/role</b></p> <ul style="list-style-type: none"> <li>▶ Viewed and treated by community as having no future</li> <li>▶ No longer considered productive member of society</li> <li>▶ Automatically associated with “social evils” (e.g., drug use, sex work)</li> <li>▶ Expected to adopt new role of teaching others about HIV and disclosing status</li> <li>▶ Loss of power, respect, and standing in community</li> <li>▶ Loss of right to make decisions about own life</li> <li>▶ Loss of marriage and childbearing opportunities</li> </ul>	<p><b>Gossip</b></p> <ul style="list-style-type: none"> <li>▶ Speculation on how person acquired virus</li> <li>▶ Spreading rumors</li> <li>▶ Whispering behind back</li> </ul> <p><b>Taunting</b></p> <ul style="list-style-type: none"> <li>▶ Insults</li> <li>▶ Mocking</li> <li>▶ Finger-pointing</li> <li>▶ Threats</li> </ul> <p><b>Expressions of blame and shame</b></p> <ul style="list-style-type: none"> <li>▶ Scolding (e.g., blamed for not listening to elders)</li> <li>▶ Blamed for bringing “bad luck” to whole family</li> </ul> <p><b>Labeling and use of derogatory words to describe people living with HIV or AIDS</b></p> <ul style="list-style-type: none"> <li>▶ In Africa: “moving skeleton,” “walking corpse,” “keys to the mortuary”</li> <li>▶ In Vietnam: “they are social evils,” “scum of society,” “deserves to die”</li> </ul>	<p><b>Loss of livelihood/future</b></p> <ul style="list-style-type: none"> <li>▶ Loss of employment</li> <li>▶ Loss of customers/business</li> <li>▶ Denial of loans, scholarships, visas</li> </ul> <p><b>Loss of housing</b></p> <ul style="list-style-type: none"> <li>▶ Denied housing</li> <li>▶ Eviction by landlord</li> </ul> <p><b>Differential treatment in schools</b></p> <ul style="list-style-type: none"> <li>▶ Teachers supporting the idea of separating children of HIV+ people to “protect” other students</li> </ul> <p><b>Differential treatment in health care settings</b></p> <ul style="list-style-type: none"> <li>▶ Excessive and unnecessary precautions by health care staff</li> <li>▶ Shuffled between providers to avoid caring for HIV+ patient</li> <li>▶ Denial of health services</li> <li>▶ Provision of substandard treatment</li> <li>▶ Use of separate medical tools for people with HIV or AIDS</li> <li>▶ Place patients with HIV in separate rooms</li> </ul> <p><b>Differential treatment in public spaces</b></p> <ul style="list-style-type: none"> <li>▶ Refusal of services (e.g., will not be served food by vendors, or not served in shared containers)</li> </ul> <p><b>Media and public health messages and campaigns</b></p> <ul style="list-style-type: none"> <li>▶ Posters and news stories emphasizing negative images of people with HIV and AIDS and employing fear tactics to warn about HIV and AIDS</li> <li>▶ Posters and news stories presenting factual information about HIV and AIDS with a moral and judgmental tone</li> <li>▶ Inflammatory news stories about HIV-positive individuals purposefully infecting others</li> </ul>

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

Expressions in public spaces include not sitting next to or moving away from a person with HIV in public transport, in places of worship, while waiting in a queue or on a bench, or at a tea shop or bar. As a woman in Zambia explained, “No one would sit next to you [on the bus]...maybe you cough and everybody [has] their eyes on you.” In places where eating together from a shared platter, sharing a communal drinking container (e.g., in Zambia, passing around a communal cup of locally brewed beer), or even sharing washed cups (e.g., tea shops in Vietnam) is common, people living with HIV and AIDS may be publicly excluded, or the usual customs visibly altered when an infected person is present. For example, suddenly individual plates or spoons and forks appear, where eating with hands from a common platter is the norm. Some actions may be very subtle, but clearly recognizable to all as being out of the ordinary. As recounted by a man living with HIV and the mother of a person with HIV and AIDS, both in Vietnam:

*I asked, “Please give me a cup of sugar cane drink” and the vendor said: “If you drink in the cup, other persons will see you drink from that cup and they won’t dare to use it. So take the drink in a [plastic] bag. (man living with HIV, Vietnam)*

*When we watched TV with them they put mosquito-killing incense beside them. Do you see? Nothing happened when others were sitting there but when we came they took the incense and put it beside them. This made us feel ashamed. (mother of PLHA, Vietnam)*

Less common, but still present, are more extreme manifestations of physical isolation including complete abandonment by family,

divorce, or separation from children. Women are more likely to experience, and therefore fear, this kind of stigma. Women’s lack of access to resources and dependence on husbands and families leaves them particularly vulnerable to abandonment, divorce, and separation from their children, and with little recourse to challenge these actions. This father of a woman with HIV in Vietnam explained that her son was taken from her in order to “protect” him from contracting the virus:

*The child is living here to avoid being infected. I let him live with us because I am frightened [that he may become infected]. It is better to make disease prevention. Supposing a mosquito stings his mother? That mosquito will continue to sting my grandchild [and so infect him]. What if there are some marks or traces of scabies and itches on my grandchild’s body and his mother scratches for him? He can be infected when the place bleeds.*

In the African urban settings, abandonment often took the form of sending a person with AIDS back to the village to “die,”<sup>15</sup> thereby often transferring the responsibility of care to usually poorer, rural relatives with less access to health care and other support services.

*I have been chased away by my husband. I have gone to our own [natal] home; even there they chased me away. I beg for assistance. You see...this illness is associated with sexual promiscuity. When I tell them at home they feel ashamed. (woman living with HIV, Tanzania)*

While physical violence against those living with HIV and AIDS, or self-inflicted violence (such as suicide), was a less frequently described form of stigma, it was one that had a deep impact when it did occur and that generated much fear and, as will be discussed later, impedes disclosure of HIV status. A woman living with HIV in Tanzania explained to an interviewer that she “felt very

<sup>15</sup> With the tradition of burying the deceased in their home village, part of this practice may be due to the fact that transporting a live person is substantially cheaper than moving a dead body.

bad to inform my partner” because “he might commit suicide or kill me, saying, ‘woman you [are] the one who brought this illness to me.’”

### 3.2.2 Social stigma

The manifestations of social stigma can be grouped into social isolation, loss of identity and role, and voyeurism. Isolation comes in various forms both in relation to important family and community events, as well as in daily life. It takes the very visible form of the disappearance of invitations to significant family and community events such as weddings, or outright orders to stay away. This woman living with HIV in Ethiopia described her experience: “I have a problem with my family, especially my father. He does not want me to participate in any kind of social life. ... He always tells me, ‘Please do not show your face to others and do not be close to our relatives.’ I think he says this for the sake of his family reputation.” Perhaps a less blatant, but equally damaging expression of social stigma is no longer being asked to participate in the planning or hosting of events. In the diaries kept by people living with HIV in Ethiopia, women were more likely than men to document experiencing this type of stigma. According to this woman living with HIV in Ethiopia:

*Last time a ceremony was conducted in the neighboring home and I went to help the women who were peeling and chopping onions and doing other things. However, they did not want me to participate and one of them told that I should get rest and the onion would burn my eyes.*

In the realm of daily life, the most common forms of social stigma were the waning or disappearance of existing friendships and the reluctance of neighbors, friends, and relatives to visit or lend or borrow common household implements and food items, important actions for survival in poor communities. A woman in Vietnam explained that she terminated all contact with a childhood friend because “people told me I should stop spending time with her. They said things like, ‘I know you have been close with her from childhood, but now she goes on that track

[sex work] so don’t play with her.’” People living with HIV and AIDS reported, and community members noted, that visits by family, friends, and neighbors tapered off, as did requests for assistance with daily needs (e.g., borrowing some salt, cooking oil, a hoe, money to get a sick child to a hospital). A man in Ethiopia explained: “They try to avoid the person by not shaking hands, turning [their] face, and showing their back and even do not exchange verbal greetings and would not sit with him in places where they go for relaxing. They will not share knives, cooking utensils, and other tools like sickle, axe.”

Another form of stigma is voyeurism. This is most frequently described in the African countries as an increase in visits to people living with HIV, particularly once AIDS has set in, where the specific intent is to see how the person is progressing in their illness and report back to the community. As a female respondent in Ethiopia explained: “When I was ill, my neighbors came and visited me, but from behind they were [talking about] me.” This voyeurism, and the fear of it by people living with HIV and AIDS and their families, can lead to increased physical and social isolation of the person, as the protective or coping reaction becomes to keep all visitors away. A woman in Tanzania explained this way: “[People go] to see someone [with AIDS] for the purpose of making amazement of him. ... Others are going there to make a mockery. They are just coming to glare at you.”

In addition to isolation, social stigma is also expressed through the taking away or diminishing of the roles, responsibilities, and social standing of those living with HIV and AIDS within the family and larger community. As a result, HIV-positive people lose power, respect, and identity. This expression of stigma is a result of both how people living with HIV and AIDS are assumed to have contracted HIV, as well as the belief that HIV means immediate disability and death. As discussed in the previous section on the causes of stigma, people with HIV are often assumed and judged to have transgressed some social norm of appropriate behavior and are automatically associated with “social evils” (IDU

and sex work) in the case of Vietnam, or promiscuity and sin in the African countries. As such, they are frequently viewed as irresponsible and immoral and therefore not fit to command respect, participate in decision making, or hold positions of authority. This view is strengthened by the widespread belief that contracting HIV means immediate disability and death, so people with HIV and AIDS have no future and can no longer be productive members of society. Put bluntly by a Tanzanian man, “When they see that someone has HIV, they see him as already dead.”

### 3.2.3 Verbal stigma

A third form of stigma is verbal. This can be direct (pointing fingers, insulting, taunting, or blaming), or more indirect (gossip and rumors). Gossip and rumors focus on speculation about whether a person has HIV, usually because of visible signs, illness, behavior, or association with groups seen as “high risk.” Once a person is assumed to be HIV-positive, people often speculate about how he or she contracted HIV. Gossip was reported to be one the most significant forms of stigma, particularly for women. As this woman living with HIV in Ethiopia noted:

*Let me tell you from my experience. In our village I am the only woman who is suspected for having the virus. However, many men are suspected and known for having the virus. But nobody seems concerned and talks about the men. They spread gossip about me.*

More direct forms of verbal stigma were expressed through insulting, mocking, taunting, cursing, and threatening those living with HIV and AIDS. They also included the expression of blame and shame, often through scolding or judgmental statements indicating people with HIV and AIDS “got what they deserved.” People living with HIV and AIDS are blamed<sup>16</sup> for becoming infected with HIV through their “irresponsible” and “selfish” behavior, and for bringing shame to themselves, their families and the community as well as becoming a burden to the family.

An integral and hurtful expression of the verbal stigma is the use of derogatory, demeaning and pessimistic or despairing language to talk about or label people with HIV and AIDS. In the African countries, where the epidemic is more generalized and has been present longer, terms commonly used to describe HIV and AIDS assume the outcome is death (*makizi yaku mochari*, or “keys to the mortuary” in Zambia); the physical appearance of a person with advanced AIDS (*maiti inayotembea*, or “walking corpse” in Tanzania); and the behaviors associated with infection and judgment of the person (*anawila posa gwila*, or “laid your hands where you shouldn’t,” in Zambia). In Vietnam, where the epidemic has been concentrated among injection drug users and sex workers, the language used focuses less on describing the physical attributes of people with AIDS and the outcome of death, and more on the behavioral aspects of HIV and judgment, using phrases like “he got his just desserts.” A fuller discussion of the stigmatizing terms documented in the data can be found in the country reports (Hong 1999; Bond, Chilikwela et al. 2003; Banteyerga, Kidanu et al. 2004; Mbwambo, Kilonzo et al. 2004).

### 3.2.4 Institutional stigma

Institutional stigma refers here to differential treatment within any broadly defined institutional setting that leads to a negative outcome for the person living with HIV. The main areas documented in the study had to do with loss of or inability to secure livelihoods, housing, health care, and education. It also includes losing access to new or future opportunities because an HIV test is required to qualify for a job, loan, scholarship, or visa for travel; differential treatment within an institution that leads to poorer outcomes (for example having to wait longer for health services); and the way those with HIV are depicted in the media. Not only do all of these forms of stigma lead to reduced life chances for people living with HIV and AIDS, but they also often serve to visibly mark a person as having HIV, exposing him or her to all the other forms of stigma discussed above.

<sup>16</sup> For more in-depth discussions on blame and shame and stigma, see Bond et al. 2003, Banteyerga et al. 2004, Mbwambo et al. 2004, and Hong et al. 2004.

### 3.3 Consequences and impact of stigma

This section explores both the impact of stigma and its consequences for individuals living with HIV and AIDS, their family members and HIV/AIDS programs. Like the causes and forms of stigma, there are differences in impact from one context to the next. These differences relate to individual personality and circumstance (everyone's experience of stigma is somewhat different, even within a given social setting); the nature and duration of the epidemic; and social, health care, and cultural contexts. The specific consequences and impact of stigma for each country setting is described in more detail in the country reports. This section focuses on the similarities across the research sites, and concludes with a brief consideration of what these consequences can and likely do mean for the epidemic more generally.

#### 3.3.1 Consequences of stigma for individuals living with HIV and AIDS

HIV and AIDS-related stigma has a wide range of consequences for people most directly affected: those living with the condition. Across all of the research sites, we found a remarkable degree of consistency in the nature of these consequences. Given the tremendous impact a disclosed HIV diagnosis can have on the life of a person living with HIV because of stigma, it is not surprising that so few people choose to be tested for HIV, and that so many of those who do test, and do test positive, try by any means to prevent their HIV status from becoming known to people around them. This section provides an overview of some of the more important consequences of stigma for people living with HIV and AIDS in our study sites.

#### Loss of livelihood

People living with HIV and AIDS in all research sites reported one of the most profound consequences of stigma was the impact it had on their ability to earn a living. People in formal employment found themselves being dismissed upon disclosure (whether voluntary or not) of their HIV status, and those selling goods or cooked food

found their client base dropping off—particularly once they began to show symptoms of HIV-related diseases. Participants in a number of the African sites reported that domestic workers with HIV were almost always dismissed. The following quotes from across the research areas are illustrative:

*...if the person is looking to be sick and she is selling at the market, people will not buy her goods—especially if she is selling cooked food. (woman, Zambia)*

*...I was working as a department head in a private transport corporation. Many drivers got HIV in that organization...and when they got sick they were fired. (man, Ethiopia)*

*Now they are afraid of me so they do not hire me [to wash clothes]. People like me cannot ask for any job. Now I do only some agricultural laboring—that is all I am doing for my living now. (woman living with HIV, Vietnam)*

#### Loss of marriage and childbearing as life options

Another disturbingly common consequence of HIV and AIDS-related stigma relates to marriage and childbearing. Spouses—particularly wives—were frequently deserted upon disclosure of their HIV status. Often this desertion was accompanied by blaming—the first person to become tested in the relationship being considered as the one who brought the disease into the home (by being unfaithful or “indulging in play”).

Unmarried HIV-positive people may find marriage no longer is an option available to them. As one woman living with HIV in Vietnam said, “Everyone dreams of having a happy marriage ... [but] because I've got it [HIV], I do not want to marry, because if I get married I would make my spouse unhappy, and I don't want that.”

Similarly, people living with HIV may find that they are strongly discouraged from having

children. In Tanzania, for example, a man in a focus group stated, “Women who are HIV-positive should not bear children.” Also in Tanzania, it was reported that sanction may be taken against those living with HIV by relatives if they bear children against their advice (Mbwambo, Kilonzo et al. 2004).

### Poor care within health sector

The forms that stigma takes in the health sector were noted in Section 3.2. There are a number of commonly reported consequences of this stigma. One such consequence is that HIV-positive people receive inferior care or are denied care altogether. For example, a nurse in Ethiopia explained:

*The wards don't have gloves, so how would you expect a nurse to go and attend to a HIV/AIDS patient? That's why you can find a patient lying in a pool of diarrhea for many hours.*

And a health worker in Vietnam admitted:

*We absolutely never inject [HIV] infected persons. We just give them medicines.... We also treat small children here, so we give [HIV] infected people no injections at all.*

A person living with HIV in Ethiopia recounted the following experience:

*I went to a dentist... [and] told him I am HIV-positive. When he heard this he told me that he cannot help me and asked me to leave his clinic.*

### Withdrawal of caregiving in the home

Health care provision in all four of the research countries suffers from serious constraints, and little can be done within the formal health sector for people living with HIV and AIDS. As a result, the bulk of the care is given within the context of the household, generally by family members and most often by a woman (see Hong, Van Anh et al. 2004). However, HIV and AIDS-related stigma can result in the refusal of family mem-

bers to provide this care—whether out of fear of transmission, out of anger, judgment and moral condemnation, fear of experiencing the stigma of others, or a combination of these factors. Intertwined with this is the impact of poverty and resource constraints, which can significantly limit the amount of care any given family is able—or willing—to provide to someone who is anyway believed to be “a hopeless case.” A further factor is the burn-out often experienced by caregivers, particularly as HIV-disease advances and the burden of care becomes increasingly demanding. The following quotes illustrate this trend:

*She was seriously ill and 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. (woman, Ethiopia)*

*There is a case of a patient of ours. He was ailing at his home where people avoided and even closed the footpath that led to his house to make sure he does not ever come to their houses, saying, “He has gotten AIDS and does not deserve to step on our land.” (home-based care provider, Tanzania)*

*Many families, although they love the child, still keep away, they are so afraid. They hire [others living with HIV] to provide care for him at the last stage, but they do not dare to provide care directly themselves. (woman FGD participant, Vietnam).*

*Household members... say it is a burden and ... some are killing their own children very fast. They leave them to die slowly, painfully...they stop buying medicine. (caregiver, Zambia)*

Despite these types of reactions, however, and despite the prevailing stigma, it was found in all sites the vast majority of people living with HIV and AIDS *did* in fact receive loving care in the context of their families (for more details on this issue see the country reports).



### Internalized stigma

Perhaps one of the most profound consequences of HIV and AIDS-related stigma for people living with the condition is the phenomenon sometimes referred to as “self-stigma” or “internalized stigma,” which occurs when a person living with HIV and AIDS imposes stigmatizing beliefs and actions on themselves. It should not be surprising that this occurs: people living with HIV are, after all, members of the same cultural, social, and moral communities as many of their “stigmatizers.” They will largely ascribe to the same values and norms, and so have the same ideas about the nature of HIV and what it means about people living with it. However, they additionally have to deal with being the object of the cruel, thoughtless, and hurtful actions of others. The near universality of this phenomenon is indicated in our research findings across these diverse settings, but also by the myriad contributions worldwide to a recent listserve discussion on the issue (see <http://archives.hst.org.za/stigma-aids>).<sup>17</sup>

It is clear that many people living with HIV and AIDS go through a process, from the initial feelings of shock, despair, shame, and grief—sometimes accompanied by denial—to (particularly if well supported) an eventual acceptance and understanding that there remains much to live for. The internalization of the stigmatizing attitudes of one’s own moral community, often at their worst during the early stages, can remain with one throughout life. While there are a great many expressions of internalized stigma, those observed commonly across our research sites included:

- ▶ **Loss of hope:** *I am in such a state—how could I get married? If I could begin my life again, nothing would make me happier. As it is, I cannot marry a wife, my economic situation cannot be regained, and my body is not healthy. So, as far as I can afford to, I just play [i.e. inject drugs].* (young man living with HIV, Vietnam)

- ▶ **Feelings of worthlessness (even suicidal feelings) and inferiority:** *He will think maybe if he dies fast it is to be better for him and he doesn’t deserve to live here on earth.* (young man, Zambia)
- ▶ **Believing oneself to be a person with no future:** *So thereafter I decided it is not worth going for studies. Why go study when I am already infected with HIV?* (woman living with HIV, Tanzania)

As the above quotes suggest, a consequence of internalized stigma can be profound depression. Upon receipt of a positive test result, and often before any symptoms appear, people may drop out of school or discontinue employment, and/or may choose to isolate themselves from their families and communities. This self-imposed isolation can be a product of the shame they are feeling, and/or out of fear of further spreading the virus through casual contact. As one woman in Ethiopia explained:

*I do not want to have close contact with people because I know that I have HIV... I am the one who should isolate myself from others. Some people who know me well want to have a good relationship with me, but I do not want to be close to them.*

A woman living with HIV in Vietnam said:

*I am afraid of giving my disease to my family members—especially my youngest brother who is so small. It would be so pitiful if he got the disease. I am aware that I have the disease so I do not touch him—I talk with him only. I don’t hold him in my arms now.*

Ultimately, HIV and AIDS-related stigma results in a loss to families and society of the unique and valuable contributions of people living with HIV and AIDS. Self-stigma thus exacerbates the serious human resource drain caused by HIV-related morbidity and mortality in highly

<sup>17</sup> The launching contribution to this discussion, submitted on December 1, 2003 (<http://archives.hst.org.za/stigma-aids/msg00045.html>) includes a useful review of the topic and a fairly extensive bibliography.

affected countries, where there are dramatic reductions in the number of essential workers such as teachers and nurses.

### 3.3.2 Consequences of stigma for the families of people living with HIV and AIDS (secondary stigma)

The consequences of HIV and AIDS-related stigma do not begin and end with the HIV-positive person, but extend to include their families, children, and even friends and caregivers. This phenomenon is generally referred to as “secondary stigma,” or stigma by association. Across all the research sites, the parents of the person with HIV were often held responsible for the “bad” behavior, which led to the HIV infection of their children. The following quotes illustrate this point:

*Some people say that the father never taught him good manners so he has ended up getting the disease. (woman, Zambia)*

*People tend to think that children get this disease when they become spoiled. It's clear that the family does not know how to educate their children. People say that the family is to blame, not the infected one. (man living with HIV, Vietnam)*

Because of this attribution of blame, as well as the close shared physical proximity, family members of people living with HIV and AIDS experience many of the same expressions of stigma as do the those living with HIV and AIDS themselves, including being the subject of gossip, being socially ostracized and isolated, and even losing income, employment, or housing. The children of people living with HIV and AIDS may bear the worst impact of stigma, sometimes being denied a place in school or being taunted, teased, and rejected by peers. Some of the consequences of HIV and AIDS-related stigma for family members observed across all research sites include:

- ▶ **Loss of livelihood:** The mother of a woman living with HIV in Vietnam used to take in neighborhood children as a day

care provider. Once the news of her daughter's HIV status became the subject of gossip, all the children were withdrawn from her care, and she had to seek alternative (and far less lucrative) employment selling lottery tickets in the city center.

- ▶ **Loss of reputation:** As indicated by the quotes above, the reputation of the family can be closely tied to the behavior of its children. Thus, when someone becomes HIV-positive, it can reflect poorly on the family, who can lose respect of the community as a result.

*... an infected person is seen as a promiscuous person, a prostitute. So when an elder wants to be praised for bringing up his family well, the praise he receives should not be that he brought up prostitutes. (woman living with HIV, Tanzania)*

A consequence of losing one's reputation in the community can be the withdrawal of key forms of social and economic support, thus further expediting a family's potential descent into poverty and/or destitution.

### 3.3.3 Consequences of stigma for HIV and AIDS treatment and prevention efforts

*The epidemic of fear, stigmatization and discrimination has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those affected. This hinders, in no small way, efforts at stemming the epidemic. It complicates decisions about testing, disclosure of status, and ability to negotiate prevention behaviors, including use of family planning services. (Mbwambo, Kilonzo et al. 2004)*

#### Impact of stigma on treatment

People living with HIV and AIDS witness, experience, and fear the seemingly limitless expressions of stigma that surround them in their

communities. Indeed, HIV and AIDS-related stigma is a phenomenon that almost all respondents, whether or not they knew their HIV serostatus, were aware of. It is clear in all sites that the presence of stigma and the fear of experiencing its effects has a profound impact on the ability and willingness of people to access and utilize the services that are available for controlling the further development of the epidemic. In all sites, for example, we found that HIV and AIDS-related stigma inhibits people from seeking treatment for infections that are closely associated with HIV, such as TB, skin rashes, and certain types of diarrhea, whether or not they have tested positive for HIV (see Bond, Chilikwela et al. 2003). As one peer educator in Zambia explained:

*It is TB, skin rashes and cancer [that are most associated with HIV]. Most people who have these diseases are shy to talk about their diseases, which makes them stay away from the clinic or the hospital to receive treatment.*

Perhaps even more worrying, however, is the impact stigma has on the willingness of people to implement prevention measures and come forward for testing. These two issues are discussed in more detail below.

### **Impact of stigma on prevention**

Sections 3.1.1 and 3.1.2 discussed the ways in which fear of casual transmission and the moral dimensions of stigma served to distance the (presumably) noninfected from people living with HIV. Fear of casual transmission has the effect of shifting the focus on to mechanisms of transmission that are largely impossible and/or those modes that are the *least* risky, but over which people have the least perceived control. The moral judgment aspect of stigma allows the (presumably) noninfected to deny their risk because “I am not like that”—as an upstanding member of the “moral community,” I could never get an infection like HIV, which only “bad” people get. If someone perceives him or herself to be at

the greatest risk through means over which he or she has no control, or if a person perceives no risk, then he or she probably will not take the measures necessary to protect against acquiring HIV. Stigma, therefore, operates in a number of ways to distance people from a sense of risk. From that vantage point, stigma creates an obstacle to prevention.

Stigma gets in the way of prevention in other ways as well. Even where there is a fairly high sense of vulnerability to HIV, stigma seems to interfere with the ability of individuals or couples to discuss condom use and use condoms regularly and correctly. Condoms themselves have acquired a strong stigma through their close association with HIV in the press and health promotion campaigns. Thus, the mere suggestion of using a condom in any given sexual encounter can be interpreted as tantamount to admitting one’s own infidelity, or that one suspects one’s partner has not been faithful. As one young man in Tanzania said:

*... in the beginning a couple might use condoms. After that most couples feel that they can trust each other [and ask], “Why should we use condoms?”*

### **Impact of stigma on testing**

HIV and AIDS-related stigma also prevents people from coming forward for testing, or when they do get tested, from returning for their test results. This relates in part to the way services are designed. For example, many people will avoid going to clinics known as HIV testing sites for fear of being seen there by others and thus suspected as having HIV. Another fear is that test results will not be kept confidential. As a man in Zambia put it:

*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.*

People also avoid testing out of fear of getting a positive result—with the stigma and other repercussions that would ensue. As one man in Ethiopia explained:

*People fear to take the blood test because if their results [are] positive, they think that people will isolate and segregate them.*

Similar feelings were expressed by a man in Tanzania:

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

### **Impact of stigma on disclosure**

A related and extremely important consequence of stigma is its effect on people's ability and willingness to disclose a positive test result to others. Across all sites, people living with HIV struggled with the issue of disclosure. In some cases, as with one woman in Vietnam, people live with the knowledge that they have HIV for years without telling even their most intimate partners for fear of stigma and its consequences, which can include physical violence and/or abandonment. As was the case for one woman, who continued to have sexual relations with her husband without condoms, and who had another child without availing herself of mother-to-child transmission prevention services, this can mean that the necessary measures are not taken to prevent the further transmission of the virus. This is echoed in the views of one respondent in Tanzania who said (in somewhat stigmatizing language): "He will go on with what he has been doing in the past. He will go on having sex with other people, and people with HIV do not show any signs that they are victims." In Vietnam, one man living with HIV observed that "Because our community does not have good feelings toward infected persons, they keep away from them. This makes me feel inferior. That's why I would like to hide [my HIV status]."

In some cases, people with HIV avoid making use of available support services out of fear that using those services would result in public disclosure of their status. As one woman living with HIV in Vietnam reported:

*The ward invited me [for counseling] several times but I did not go because I am reluctant to meet people there... It is normal for a drug addicted person to be infected. But for me, people tell each other, "Look, such a girl but yet infected." So I feel reluctant. I do not want to go [to the ward's activities for those living with HIV].*

It is interesting to note that across all sites, the wider community seemed to feel that people testing positive with HIV *should* disclose their status publicly. As a newspaper in Tanzania reported: "When a person suffers from AIDS it is better to disclose. So himself or his relatives should disclose the truth to the community so the disease does not spread to others." In Vietnam, the general sentiment was that if a person's status was not known, the community would not be able to provide the support to that person and his or her family, as is encouraged by the government. However, in all sites it was well understood by the community that disclosure was difficult and even dangerous due to HIV-related stigma.

This section has reviewed a number of the main consequences of HIV and AIDS-related stigma identified in our four studies for people living with HIV, for their families and close friends, and for HIV and AIDS programming. The study findings indicate that HIV and AIDS-related stigma is an important obstacle for prevention, impeding people from getting tested for HIV or from disclosing their HIV status to others. Although anti-retroviral treatment (ARV) was not widely available in any of the research sites at the time these studies were conducted, evidence is now emerging from a number of ARV pilot sites indicating that there, too, stigma is an

obstacle. It was certainly an issue for the use of prevention in mother-to-child treatment programs in Botswana and Zambia (Nyblade and Field 2000). Clearly, therefore, HIV and AIDS-related stigma is having an important impact on

the epidemic as a whole—operating as a key *driver* of the epidemic. Thus, combating stigma is a matter of utmost urgency for all HIV programs to address.

## 4

## Conclusions

This report has compared research findings from four countries with different social, economic, political, historical, and geographic contexts, each with a different experience of the HIV/AIDS epidemic. A key finding is that HIV and AIDS-related stigma and discrimination are remarkably consistent across contexts. Although there are some notable variations in stigma that stem from differences in language, culture, and epidemic history, these differences are largely of nuance and degree rather than substance. Instead, we find commonalities in what *causes* stigma, the *forms* in which stigma is expressed, and the *consequences* of stigma. Therefore, attention is given here to the implications of this finding for the development of interventions intended to reduce stigma and/or mitigate its impact.

To date, efforts to reduce HIV and AIDS-related stigma and discrimination have not adequately matched the magnitude and apparent universality of the problem. Parker and Aggleton quote an unpublished USAID document that contains a suggested reason: “The problem [HIV and AIDS-related stigma] is a difficult one, because underlying the apparent universality of the problem ... there appears to be a diversity and complexity that makes it difficult to grasp in a programmatically useful way” (USAID 2000, in Parker & Aggleton 2003:14). Our research findings indicate that differences are largely superficial and need not stand in the way of developing programs and interventions.

## 5

## Recommendations

Two basic approaches to tackling stigma have thus far been offered in the literature: either individual change or structural change. Our data and experience indicate that an effective response to stigma needs to include both. In fact, one way to accomplish structural change is through the individual. Using such a combined approach, programs and policy should address the two key underlying causes of HIV and AIDS-related stigma described in this report: (1) knowledge and fear; and (2) values, norms, and moral judgments. People living with HIV also should be involved in the development and implementation of all stigma-reduction programs. The following is a discussion of four broad recommendations that can be applied to all stigma-reduction programs and policy.

### 5.1 Individual and structural change

Some researchers have criticized stigma interventions that focus only on the individual (e.g., Parker and Aggleton 2003). The primary thrust of this critique is that stigma is about “marking of significant differences between categories of people,” which has its foundations in “systems or structures of power” and must be understood as “central to the constitution of the social order” (Parker and Aggleton 2003). These critiques call for an approach that considers the structural relations that produce and reproduce stigma and social exclusion. A myriad of other structural issues also contribute to stigma and discrimination and perpetuate social inequalities, not the least of which is poverty.

While we fully agree that addressing structural issues is fundamental to mitigating stigma, this and other research and results emerging from ongoing pilot interventions indicate that it is not sufficient to intervene *only* at the structural levels. While power relations that foster inequal-

ity are structural, they are perpetuated by *individuals*, individuals who are well placed to institute change if motivated to do so and given a supportive environment. We thus call for an approach to intervention that starts with the conviction that individual attitudes can and do make a difference, and that long-term and far-reaching stigma reduction can start with individuals. Depending on the context, it may be necessary to intervene with people in positions of power and influence; people who determine to a large extent what messages are delivered and how; people who have the power to institute anti-discrimination laws and policies; and people who are charged to carry out these laws and policies. In *all* contexts, it will be appropriate and necessary to intervene at the community level with community members, including health care workers, people working with faith-based and community-based organizations, and people living with HIV and AIDS and their families.

### 5.2 Knowledge and fear about HIV and AIDS

The persistence across diverse settings of the “*knowing, but not quite believing*” that HIV can only be transmitted through three specific routes indicates that overcoming these doubts and fears is one of the key steps for any program working to reduce HIV-related stigma. The continuation of stigma driven by these fears, despite years of information, education, and communication (IEC) and more recently behavior change communication (BCC) efforts, indicates that current strategies for imparting an understanding of HIV transmission, and AIDS more generally, are not completely effective, and in some cases may be contributing to fear and stigma. More specifically, the findings suggest that programs need to focus on the substantive

content of messages pertaining to HIV as well as the style and method of delivery, paying attention to the following:

### Substantive content of messages

Persistent fears about HIV transmission through improbable means, and the “what if” scenarios people create in the face of these fears, indicate that many people dwell on and worry about HIV transmission through casual encounters in daily life. These unfounded fears clearly suggest that partial or ambiguous (and often negative) information contained in HIV and AIDS-related messaging can have unintended, and undesirable, consequences. Thus, programs and policies need to broaden, deepen, and sharpen HIV messages by:

- ▶ Providing information not only on how HIV *is* transmitted, but also how it is *not* transmitted. This includes identifying the most commonly feared “casual” contact situations in a community (e.g., contact with blood, sweat, and saliva where no fluids are exchanged, or mosquitoes) and explaining *why* HIV transmission is highly unlikely or impossible through these situations.
- ▶ Ensuring that people have a deep enough understanding of what HIV is and how it is transmitted so that they are equipped to make correct assessments of actual HIV risk in any given life situation they encounter. For example, understanding that HIV is unable to survive for long outside the body will help reassure people that HIV cannot be transmitted through various modes of casual contact experienced on a routine basis, such as sitting next to a person with HIV on a bus or sharing utensils with a person with HIV. This is an especially important message to get across because people in all four studies expressed fear of transmission through casual contact, and many forms of stigma are directly related to that fear.
- ▶ Delivering clear and unambiguous information by explaining exactly how HIV is transmitted through blood and sex, or from mother-to-child, to ensure a clear

understanding of risky exposures and the relative risks of different exposures. The ways in which HIV can be transmitted are often presented in ambiguous terms (sex, blood, mother-to-child), with little distinction made between the relative risks of the three modes or of the relative risks of different kinds of contact within a given mode (e.g., blood exposure through injection or transfusion versus blood left on a nail clipper).

- ▶ Broadening the content of HIV messages to include information on HIV and AIDS beyond transmission, in particular, what it means to live with HIV; the skills needed to help individuals prevent its transmission; and if infected, how to live healthy and productive lives. For example, messages could inform about the longevity of a person living with HIV or that opportunistic infections are treatable in HIV-positive persons. Messages also could offer practical tips on different strategies for bringing up the issue of HIV and condom use with sexual partners, both in steady partnerships and casual relationships.
- ▶ Creating recognition and understanding of HIV stigma, including what it is; how it is harmful to ourselves, our families, and our communities; and the role each individual has to play in reducing it. While not dealt with in-depth in this report,<sup>18</sup> the data from all countries shows a gap between people’s stated intentions *not* to stigmatize and their actions, which are stigmatizing. This indicates a lack of recognition of what stigma actually is. Creation of improved awareness of what stigma is and fostering an understanding of how stigma is harmful would help stop this inadvertent stigma from occurring. At the same time, addressing each individual’s role in creating or reducing stigma would generate the necessary will to do something about it.

### Style and delivery of messages

In addition to the content of HIV and AIDS information, the style and delivery of messages also potentially creates and perpetuates stigma.

<sup>18</sup> See Nyblade et al. 2003 for a more detailed discussion of this point.



In this respect, the findings suggest the following critical areas to address in working toward reducing HIV-related stigma:

- ▶ Provide HIV and AIDS information in an interactive format, moderated by a knowledgeable and trusted facilitator. This will encourage discussion, questions, and feedback on the hypothetical scenarios that people worry about. Such a format allows the facilitator to address all individual concerns and unambiguously dispel the notion that HIV can be transmitted through casual contact. Once people truly understand and believe this, they will be less likely to stigmatize people with HIV through avoidance and isolation. Messages delivered in a uni-directional mode (e.g., through billboards, fliers, posters, radio, etc.) are important but need to be complemented by opportunities to ask questions about the information to dispel any misunderstandings the information creates about casual transmission.
- ▶ Gather data on how people understand the messages they receive, whether from specific IEC or BCC campaigns or from the growing global flow of information through the Internet and other communication outlets. A regular process of collecting this kind of information is critical so that misconceptions can be dealt with quickly, before harm is done.
- ▶ Use more positive images of people living with HIV, rather than fear-based messages and negative images. The findings confirm that the use of fear-based messages that equate HIV infection with disfigurement, suffering, and death, and images of sick and dying people with AIDS only serve to increase the fear of HIV and people with HIV. Eliminating fear-based and negative imagery will increase positive images of persons living with HIV and combat the fear that drives

stigma, as well as the stigmatizing beliefs that HIV equals immediate disability and death, and that persons with HIV are nonproductive members of society.

### 5.3 Values, norms, and moral judgments

To effectively address stigma, programs and policy also must attempt to disassociate HIV from the sensitive and often taboo social issues that are associated with its transmission, in particular sex and injection drug use. This can be done without sacrificing effective communication of information about prevention. For example:

- ▶ Explain how HIV is (and is not) transmitted in a fact-based, neutral and nonvalue-laden format.
- ▶ Messages, programs and policies need to discuss the behaviors that can lead to HIV transmission without direct reference to particular individuals or groups to ensure that specific groups (e.g., young girls, gay men, sex workers, injection drug users) are not singled out as vectors of transmission. Messages about HIV that include implicit value judgments about a behavior legitimize stigma by implying that HIV is a matter of personal choice.
- ▶ Create safe, facilitated spaces to discuss the values and beliefs that underlie stigma. The values, norms, and moral judgments that create and justify stigma are ingrained and often unconscious. Tackling stigma requires facing these issues, including reflecting on:
  - Why we hold these judgments and their negative effects;
  - How judgments keep us from accepting and caring for people with HIV, even those close to us;
  - The fact that the nature of HIV puts us all at risk, and that making morality-based

distinctions of “us” versus “them” does not protect us, but instead puts us at greater risk by creating a false sense of distance; and

- How the position of women in society, particularly the double standards for men and women, lead to increased stigma (and vulnerability) for women.
- ▶ Key institutions and opinion leaders shaping and reinforcing societies’ values must take the lead in reducing stigma. They can do this by:
  - Promoting nonstigmatizing principles like compassion and nondiscriminatory and equal treatment for all;
  - Carefully examining content and style of

#### **Box 4: Understanding and Challenging HIV Stigma: Toolkit for Action**

The lack of tools to guide responses to stigma has hampered and delayed past action. To address this need, a set of practical tools was developed, contained within the Anti-Stigma Toolkit: Understanding and Challenging HIV Stigma: Toolkit for Action. These tools are based on findings from the four country studies and provide sound, evidence-based guidance for launching stigma-reduction activities with key groups, including religious and political leaders, people living with HIV and AIDS, and community members. Participatory exercises address the knowledge and value issues that underlie stigma and create the necessary awareness of stigma to motivate action. The intent is to motivate people in positions of power and household and community members to use these methods to address the stigma around them.

##### **The toolkit’s central themes address the causes of stigma:**

The toolkit emerged from the Africa research project and is designed to address key research findings about the causes of stigma. In particular, it assists efforts to:

- Make stigma visible and assist in resolving contradictions such as those between intentions and behavior;
- Enhance practical knowledge to reduce fear of casual transmission;
- Provide a safe forum to discuss sensitive topics (sex, death, drug use, inequity);
- Find a common language to talk about stigma;
- 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; and
- 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 toolkit was developed through interactive, participatory workshops in all three African countries, with a total of 75 participants from 50 NGOs. Led by Ross Kidd and Sue Clay, CHANGE/AED, ICRW, Miz Hasab, MUCHS, ZAMBART, and KCTT coordinated the effort. The toolkit since has been adapted for use in Vietnam by the Institute for Social Development Studies, with the support of ICRW and Ross Kidd. The first edition was developed in Africa and is available in English and Kiswahili. An adaptation of the first edition for the Asian context has been completed and is available in both English and Vietnamese.

The entire Toolkit can be found at: [www.changeproject.org](http://www.changeproject.org).

messages (as described above) to ensure they are nonstigmatizing; and

- Training leaders to improve their understanding of HIV and overcome fears of casual transmission, recognize stigma, and become motivated to tackle it, and begin the process of self-reflection on values, morals, and judgment.

#### **5.4 Involve people with HIV and AIDS as integral members of all programs**

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, those living with HIV have the life experience and knowledge needed to design and implement appropriate stigma-reduction responses. Where appropriate,<sup>19</sup> with training (where needed) and support, and as paid staff members or consultants, people with HIV should form the core of stigma-reduction programs. 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 this report point to the critical role people living with HIV have in dispelling the myths that allow stigma to persist. In particular, they can help combat the fear of casual transmission of HIV, the belief that HIV means immediate disability and death, and that people living with HIV are somehow different from everyone else. In addition, working to fight HIV and stigma is an empowering activity that gives hope to people with HIV, which also helps people overcome internalized stigma.

#### **5.5 The way forward**

The research evidence presented in this report indicates that it is time to stop making excuses for not addressing HIV and AIDS-related stigma and discrimination. Stigma is certainly complex and affected by context. However, as these studies show, there are more commonalities than differences in the causes, forms, and consequences of HIV and AIDS-related stigma across countries and continents. Taking the opportunity to design and implement interventions that address these common issues and understandings is the first step in reversing the devastating impact that stigma is having on those infected with and affected by HIV and AIDS. The time to act is now.

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<sup>19</sup> Involvement of people with HIV in stigma-related efforts needs to be done in a manner that is respectful, safe, voluntary, and contextually appropriate. The presence of stigma means that public participation comes with potential harmful consequences, and programs need to recognize this and be prepared to respond and support their employees living with HIV should negative outcomes occur. Programs also need to ensure that people with HIV are not coerced in any manner into disclosure or participation, including recognizing that in the context of poverty, the need for a job and benefits may force open disclosure before it is safe and appropriate.

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**International Center for Research on Women**

1717 Massachusetts Avenue, NW  
Suite 302  
Washington, DC 20036, U.S.A.

**Tel:** (202) 797-0007

**Fax:** (202) 797-0020

**e-mail:** [info@icrw.org](mailto:info@icrw.org)

**[www.icrw.org](http://www.icrw.org)**



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