

## 2. DEFINING THE ISSUE

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*“HIV-related stigma may well be the greatest obstacle to action against the epidemic, for individuals and communities, as well as political business and religious leaders. An all-out effort against stigma will not only improve the quality of life of people living with HIV and those who are most vulnerable to infection, but meet one of the necessary conditions of a full-scale response to the epidemic.”*

(UNAIDS: Piot & Seck, 2001)

### 2.1. Stigma and discrimination

#### 2.1.1. Stigma

Stigma is as old as history. The concept is universal, although the origin of the word is Greek and refers to the physical mark made by fire or with knives on individuals considered outsiders or inferiors. Today the physical marks have gone, but stigma remains, based on one or more factors, such as age, caste, class, color, ethnicity, religious belief, sex and sexuality. Stigma, defined as a “deeply discrediting” attribute in the landmark study by Erving Goffman (1963) is applied by society and borne or possessed by groups and individuals. Stigma may be associated with specific acts, such as adultery or criminal behavior, with inherent qualities such as sex or skin color, or with quasi-inherent qualities, such as religion or nationality.

Some diseases and other health conditions often lead to stigma, affecting particularly people with mental illnesses and physical disabilities. In addition, stigma is sometimes associated with social stereotypes - the sometimes positive, sometimes negative, “short-hand” images that we all use to identify strangers and which determine our reactions to them.

Stigma is a means of social control, defining social norms and punishing those who deviate from the norm. At the heart of stigma lies the fear that those who are stigmatized threaten society. Underlying that fear is often ignorance, such as

ignorance of the way of life of HIV/AIDS stigmatized groups or ignorance of the realities of sexual behavior or the way in which diseases spread.

The word stigma is used by social scientists more than the general public. In English, in everyday speech, it has been replaced by such words as sexism and racism, which carry related but different meanings. And while in some societies some stigmas have weakened – it is, for example, much easier to be openly homosexual in an urban society in the West now than it was fifty years ago – in other societies stigma persists. Lower caste remains a marker of stigma in Indian culture, women are stigmatized in many societies and homosexual men are still the subject of ridicule and violence in many parts of the world. Stigma can be additive; to be a poor illiterate woman, for example, is worse than any of these conditions taken individually.

Although the concept is negative, stigma can have positive consequences. It can create a sense of community among stigmatized individuals, motivating them to support each other and make changes that will improve their lives. Stigma and persecution have been the cause of much migration, such as that of Jews to the United States in the late nineteenth and early twentieth centuries. In more recent years, dalits (“untouchables”) in India and homosexual men in many parts of the world have responded to stigma by demanding the right to live as full and equal citizens in their own societies.

Even though stigma may appear constant, it is more accurately described as a process. (Parker &

Aggleton 2001) New stigmas arise and others fade as changing knowledge and power structures lead to new hierarchies and social norms. Sex between older men and pubescent boys was once acceptable in many societies across the world but is now almost universally condemned. The stigma against Jews in many Western societies is considerably weaker than it was a hundred or a thousand years ago. And the form and intensity of HIV/AIDS-related stigma continues to fluctuate.

### 2.1.2. Discrimination

The original meaning of “discriminate” was to note differences. Over time, however, the word has come to mean to perpetrate an unjust action or inaction against individuals who belong, or are perceived to belong, to a particular group, in particular stigmatized groups.

Discrimination can be legislative – enshrined in law or policy – or community – actions or inaction in less formal contexts, such as the workplace or social settings such as a marketplace, sports center or bar.

International norms also provide definitions for discrimination. The “Inter-American Convention on the Elimination of All Forms of Discrimination

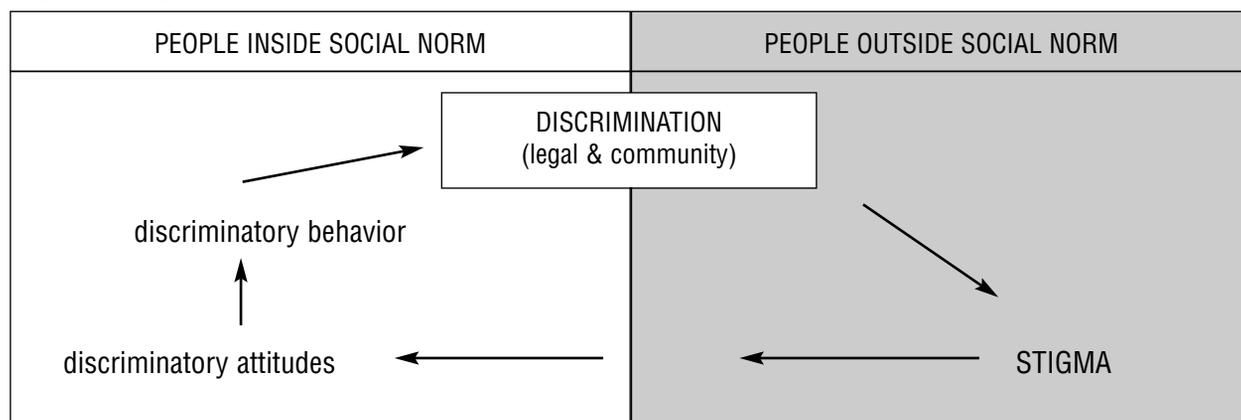
Against Persons With Disabilities” considers discrimination to be “any distinction, exclusion, or restriction” that violates the human rights and fundamental freedoms of the person.

Discrimination consists of three components: discriminatory attitudes (also known as prejudice), discriminatory behavior and discrimination. The first two (discriminatory attitudes and behavior) apply to individuals within the social norm, while the last (discrimination) applies to the relationship between those within the social norm and those who are stigmatized. (See Figure 1)

As Figure 1 suggests, stigma and discrimination exist in a vicious circle. Stigma allows or encourages discriminatory attitudes. These attitudes are often reflected in discriminatory behavior that results in acts of discrimination. Acts of discrimination draw attention to or increase stigma.

Sometimes, however, the pattern of stigma and discrimination is broken. It is possible for someone to suffer stigma but not discrimination, for example when legislation prevents stigmatized groups, such as an ethnic minority, being treated differently from other members of society. And attempts to reduce stigma may reinforce it, for example, when university quotas are reserved for members of underprivileged communities<sup>4</sup>.

**Figure 1: Stigma and discrimination: an overview**



<sup>4</sup> This argument, that positive discrimination can increase stigma, is not universally accepted.

### 2.1.3. “Felt” and “enacted” stigma

Attempts to analyze stigma and discrimination have led to narrower definitions that are not always universally understood, such as the distinction between “felt” and “enacted” stigma. (Scrambler & Hopkins 1986, Jacoby 1994, UNAIDS 2001) Felt stigma – which has also been referred to as self-stigmatization and as fear of stigma – refers to the expectations of stigmatized individuals as to how others will react to their condition. Felt stigma leads people to hide their stigmatizing condition, if possible, which limits the extent to which they experience discrimination. Meanwhile, enacted stigma is defined as actual experience of stigma and discrimination.

However, while “felt stigma” is a useful term that describes internal perceptions of stigma, “enacted stigma” is no more than an alternative term for discrimination. Furthermore, it can lead to confusion since it is the individual outside the social norm who “feels” stigma, but the individual or institution inside the social norm who “enacts” it - i.e. discriminates. “Experienced stigma” is a more appropriate term to describe discrimination from the affected individual’s point of view and it is used in place of “enacted stigma” in this document.

In other words, felt stigma is internal - how people outside the social norm perceive their status – while experienced stigma is external – how the same people experience discriminatory acts.

## 2.2. Stigma, discrimination and HIV/AIDS

The link between stigma, discrimination and HIV/AIDS has long been recognized. The London Declaration, issued in 1988 by the World Summit of Ministers of Health on Programmes for HIV Prevention, was one of the first international statements to recognize that “[d]iscrimination against, and stigmatization of, HIV-infected people and people with AIDS and population groups undermine public health and must be avoided.” (para 6) That principle has been reiterated by many international bodies

since then, including the World Health Assembly of the World Health Organization and the Commission on Human Rights and was confirmed by the United Nations General Assembly Special Session on HIV/AIDS held in 2001.

### 2.2.1. Causes

Stigma has long been associated with diseases that provoke strong emotional responses through their association with disfigurement, such as leprosy and polio, and death such as cholera. As the cause of both disfigurement (wasting syndrome, Kaposi’s sarcoma etc) and death, HIV/AIDS provides fertile ground for stigma to take root. That stigma increases where there is ignorance as to how HIV is transmitted, leading individuals and communities to fear casual contagion through such actions as shaking hands, coughs and sharing eating and toilet facilities.

Disease-related stigma<sup>5</sup> can be reduced by education. A consistent finding in studies is that people who have little knowledge or are misinformed about HIV transmission are much more likely to hold discriminatory attitudes than those who are well informed. In other words, people who are aware that casual contagion is impossible are less likely to hold negative attitudes towards people with HIV/AIDS. (CDC 2000; Herek et al 2002)

A weakening of the association between HIV/AIDS and death also reduces stigma. Anecdotal evidence from several communities suggests that discrimination falls where people with the virus have access to the antiretroviral and other drugs that prolong life and make disfigurement less likely.

However, while some sources of prejudice fall away, others remain. HIV/AIDS is also linked to long-standing stigmas of sexual misconduct and, in some communities, illicit drug use. “People with HIV/AIDS are often believed to have deserved what has happened by doing something wrong. ... Men who become infected may be seen as homosexual, bisexual or as having had sex with prostitutes. Women with HIV/AIDS are viewed as having been ‘promiscuous’ or as having been sex workers.” (UNAIDS 2002a)

<sup>5</sup> From this point onward, unless otherwise specified, stigma and discrimination refer to HIV/AIDS-related stigma and discrimination

Such stigmas persist, irrespective of the reality. In the United States, where sex between men accounted for less than 40% new cases of HIV transmission in 1997, up to 67% of one sample in a public survey admitted that they primarily associated the disease with homosexual men. Heterosexual men who contracted the virus were the subjects of less disapproval than homosexual men in the same position. (Herek & Capitanio 1999)

These two components of HIV/AIDS-related stigma – disease and pre-existing stigma – have led some commentators to distinguish between instrumental AIDS stigma and symbolic AIDS stigma. The former reflects fear of HIV/AIDS as a communicable and fatal disease; the latter results from the association the disease has with groups already stigmatized. (Herek 1999).

*In rural Zambia, powerful imagery, metaphors and euphemisms for HIV/AIDS include terms associated with immorality, illness, death, denial, innocence and guilt. “Dominant in such discourse is the blame assigned to people with HIV/AIDS, and assumptions made about their past sexual history. Exceptions [are] grandmothers who assist women in labor and ‘deserve pity’ if they become infected.”*

—(Panos / UNICEF, 2001)

### 2.2.2. Those affected

HIV/AIDS-related stigma affects men and women, young and old, rich and poor. It affects people known to have contracted the virus, people suspected of having contracted it or of being vulnerable to the virus, such as sex workers and homosexual men, and the families and caregivers of those who are ill. It occurs in every country, irrespective of the extent and impact of the epidemic itself. “One of the most surprising elements of AIDS stigma is its ubiquitous nature even where the epidemic is widespread and affecting so many people, such as in sub-Saharan Africa”. (Brown et al 2003)

As the examples given here show, stigma and discrimination affect different groups in different ways and at different stages of the disease.

#### *Hemophiliacs*

In theory, hemophiliacs and others who contract the virus through contaminated blood products are less stigmatized than those who contracted HIV through sex or injecting drugs. In practice, however, hemophiliacs with HIV/AIDS report incidents of discrimination no less hurtful than those experienced by others with the virus.

#### *Children*

Children infected with HIV in the womb are also theoretically less stigmatized than adults. The reality is, however, that children with HIV who are orphaned or abandoned are seldom adopted in some communities, and those who are known to be or are suspected of being HIV-positive have been turned away from school.

#### *The poor*

Poverty increases vulnerability to HIV. The lack of economic opportunities may lead to commercial or transactional sex, while poor education hinders prevention activities. In some cases, people want to buy condoms, but cannot afford them. As a result, poor people with HIV are often labeled as hopeless and irresponsible. In addition, poor are generally regarded as less “deserving”.

#### *Women*

Women who sell sex are stigmatized in most societies, whether or not they have contracted HIV. That stigma is often extended to the many women who contract HIV from their husband or long-term partner – HIV infection is so strongly associated with promiscuity that women with the virus are frequently assumed to be promiscuous, irrespective of their sexual history. When HIV is diagnosed, “men are more likely to be accepted by family and community. Women ... are more likely to be blamed, even when they have been accepted by their husbands in what for them have been monogamous relationships.” (UNAIDS 2001)

However, even though women face greater stigma, anecdotal evidence suggests that in communities where sex between men and women is the primary form of HIV transmission, women with the virus have stronger support networks and are likely to live longer after diagnosis than men. In communities where sex between men is the primary source of transmission, men tend to have stronger support networks. (Foreman 1999)

### *Homosexual men*

Homophobia, which is generally defined as fear, hatred or disapproval of sex between homosexual men<sup>6</sup>, preceded HIV/AIDS-related stigma and discrimination and, as is noted several times in this report, continues to be strongly associated with the disease<sup>7</sup>.

The stigma and discrimination associated with sex between men affects such men in two different ways – lack of services and reluctance to access services. HIV/AIDS services for men are either absent in many communities, particularly in Africa and parts of Asia, or are insufficient, as in Latin America, where men who have sex with men comprise less than 10% of the population but 35% - 65% of reported cases of HIV. Where services are available, stigma and discrimination related to sex between men prevents many from accessing appropriate HIV/AIDS counseling, testing and care services. (Chakrapani 2002, Vivo Positivo 2002)

In some circumstances, homophobia even affects men who have only sex with women. There

are several reports of heterosexual men, particularly in Latin America, who are reluctant to work with people with HIV/AIDS or who are afraid of contracting the virus in a non-sexual setting (such as occupational exposure in a hospital) because they fear others will suspect they are homosexual.

### *Injecting drug users*

There is considerable anecdotal evidence and some statistical evidence that underline the extent to which injecting drug users are the victims of stigma and discrimination, irrespective of HIV/AIDS. Drug users are often unable to access appropriate HIV/AIDS prevention and care services.

“One of the few reports which has examined discrimination against injecting drug users ... found that, of 300 injecting drug users interviewed in New South Wales, Australia, “ill treatment” had been experienced from police (80%), hospital staff (60%), doctors (57%), pharmacists (57%), employers (47%), dentists (33%), methadone providers (33%), drug treatment services (33%) and community health workers (7%). As the report noted: ‘Experiences of discrimination are so common and relentless many users fail to then recognize they are being discriminated against. It seems normal to be treated badly and vilified if you’re a user.’“(Burrows 2003b)

*It has been suggested that the extent of stigma attributed to society and the extent to which the individual affected acknowledges or avoids stigma differs at different stages of HIV infection:*

- *at risk: belonging to a group at high risk of infection but not taking an HIV test;*
- *diagnosis: confirmation of HIV infection;*
- *latent: HIV-positive but without symptoms of AIDS;*
- *manifest: with symptoms of AIDS and approaching death. (Alonzo & Reynolds 1995)*

*Because antiretroviral drugs significantly reduce the association of HIV/AIDS and death, the latter stages of this model may be modified in societies where these drugs are available.*

<sup>6</sup> While the expression “men who have sex with men” is usually used in preference to “homosexuals” or “bisexuals” to make the point that not all men who have male sexual partners perceive themselves as homosexual (or gay) or bisexual, stigma and discrimination affect particularly those with homosexual identity.

<sup>7</sup> While there are many strands to homophobia, a key factor is repressed homosexual tendencies – many men who are homophobic are afraid of recognizing that they themselves are to some extent attracted to men.

### 2.2.3. The impact of stigma and discrimination

Whether the result of specific legislation or policy, or the spontaneous act of individuals within the social norm, discrimination against people living with or associated with HIV is widespread and takes many forms. In addition to discrimination in health care settings described in Chapter 3, discriminatory acts include:

- Refusal of education
- Refusal of or removal from employment
- Denial of the right to marry
- Requirement to submit to an HIV test for work, travel or other purposes
- Lack of or reduced confidentiality
- Detention
- Deportation
- Demonization in the media
- Rejection by families, friends and communities
- Physical attack, including murder

Such acts have negative impact on the community and individual health. In some cases they may constitute an obstacle to the exercise or enjoyment of human rights and fundamental freedoms. In other instances they are per se a violation of such rights and freedoms.

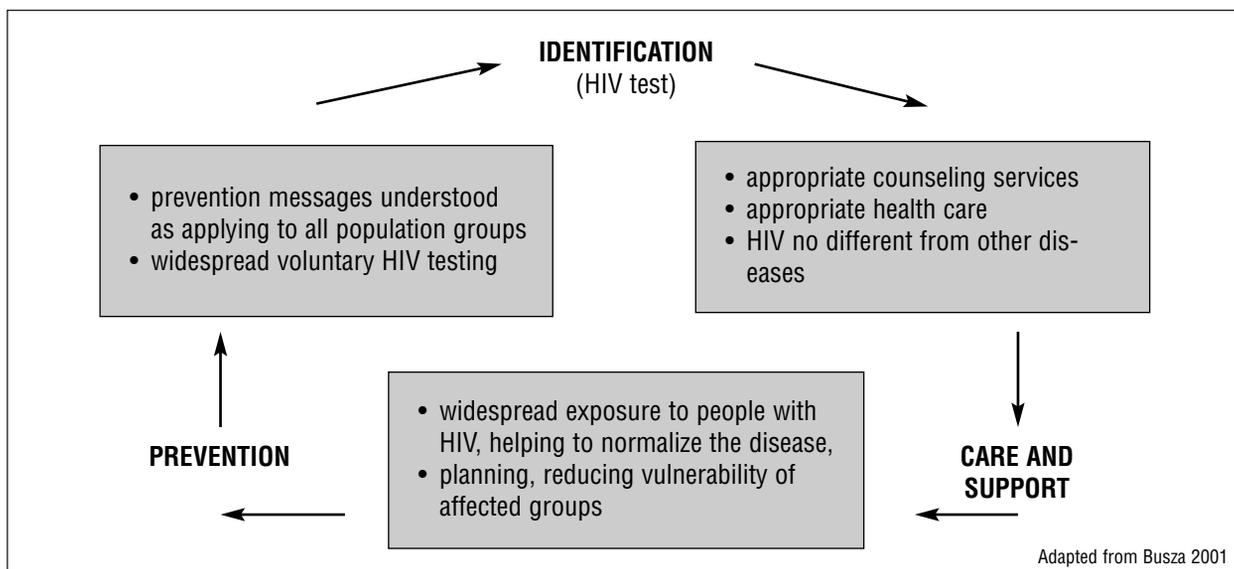
### *Individual and public health*

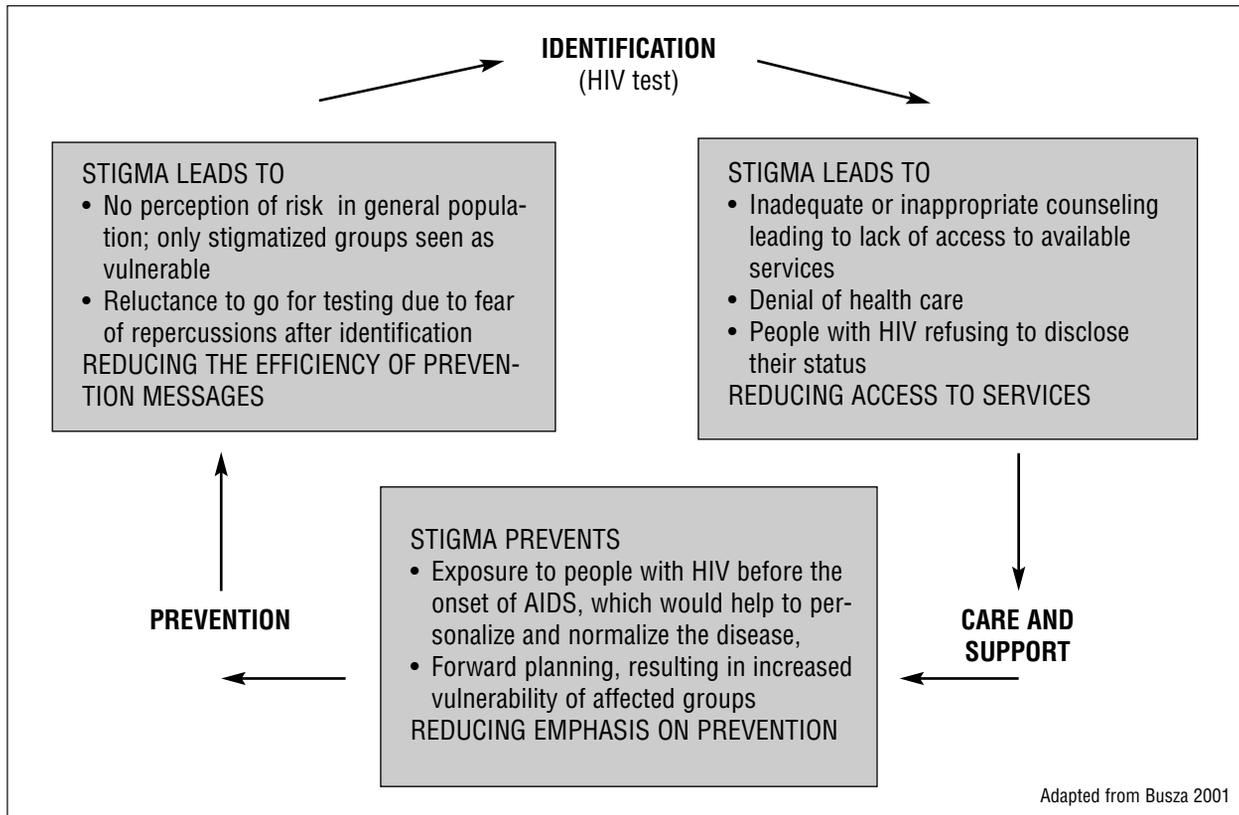
In an ideal world, prevention and care exist on a continuum whereby those at risk are encouraged to test for HIV infection, those who are found positive receive appropriate counseling services and those who are cared for are accepted by the community, creating an appropriate environment where those at risk are encouraged to test for infection and so on. (Figure 2a)

In reality, however, stigma interrupts this continuum by discouraging individuals from testing for the virus, reducing the options for care and support and limiting the input into prevention programs (Figure 2b). The result is that both individual and public health suffer.

To examine one component of the impact in stigma in greater detail: voluntary testing for HIV, the first essential step in protecting one's health. Whatever the result, people who take the test are more likely to practice safer sex and / or safer injecting practices. (Hays et al 1997, Janssen 2001) And people who know they are HIV-positive can access available treatment and maintain a better quality of life. In many countries, however, a large number of people living with HIV have not been tested and so are unaware of their status. In the United States it is

**Figure 2a: The Prevention to care continuum: ideal scenario**



**Figure 2b: The impact of stigma on the prevention to care continuum**

estimated that at least one in three people living with the virus are unaware they are infected (CDC 1999) Similar or higher figures have been reported from Europe. (Castilla et al 2002, Hamers et al 1998)

While many people do not take the test because they are afraid of learning they are suffering from a fatal disease, particularly where antiretroviral therapies are not available, stigma and discrimination also play a role. Many of those who know they are at high risk are dissuaded by fear of being identified as HIV-positive or as a member a stigmatized group such as homosexual men. And the association between HIV/AIDS and stigma leads many people inside the social norm to consider themselves unaffected by the disease and to continue the practice of unsafe behaviors that place them at risk.

In other words, because it reduces the motivation to get tested and to look after one's own health, stigma and discrimination allow HIV to spread, with serious consequences for both the individual

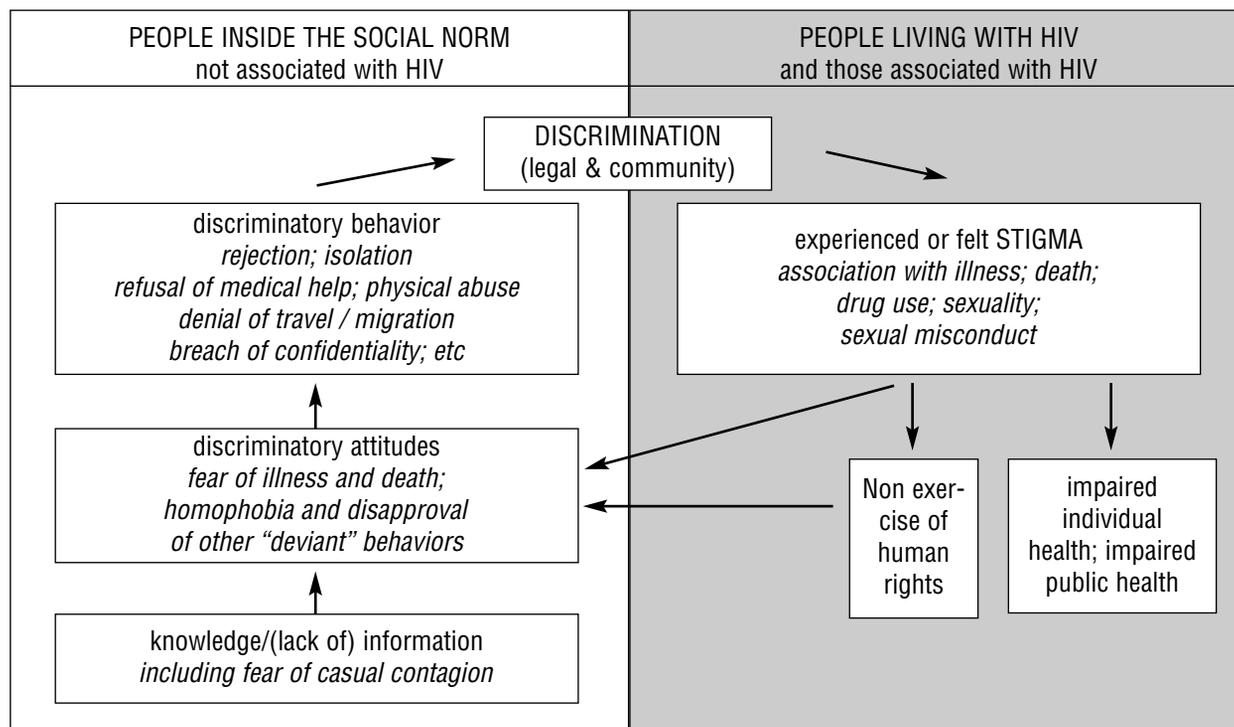
and the community. Furthermore, stigma and discrimination may have strong psychological consequences on those who are HIV-positive, increasing social isolation and depression. (Lichtenstein et al 2002, UNAIDS 2002a)

#### *Human rights*

In general, there are many links between health and human rights. Violations or lack of attention to human rights can have serious health consequences, and health policies and programs can promote or violate human rights in the ways they are designed or implemented. Steps to respect, protect and fulfill human rights can reduce vulnerability to and the impact of ill health. (WHO 2002)

HIV/AIDS and human rights are intimately linked. On the one hand abuse of human rights can lead to vulnerability to HIV/AIDS, as when those at risk are denied the right to appropriate health information and care; on the other hand, being HIV-positive can lead to a non-exercise or non-enjoyment of

**Figure 3: HIV/AIDS-related stigma and discrimination**



human rights, as when those who are living with the virus suffer one or more of the acts of discrimination identified above.

Many international bodies, in particular the United Nations Commission on Human Rights in its resolutions 1999/49, 2001/51, 2002/31, have confirmed that the various international instruments on human rights cover health status, including HIV/AIDS. The vast majority of nations, which has ratified these instruments, have thereby committed themselves to upholding the human rights of people living with HIV/AIDS. Other international treaties in this area are the American Convention on Human Rights, the European Convention on Human Rights and Fundamental Freedoms and the African Charter on Human and People’s Rights.

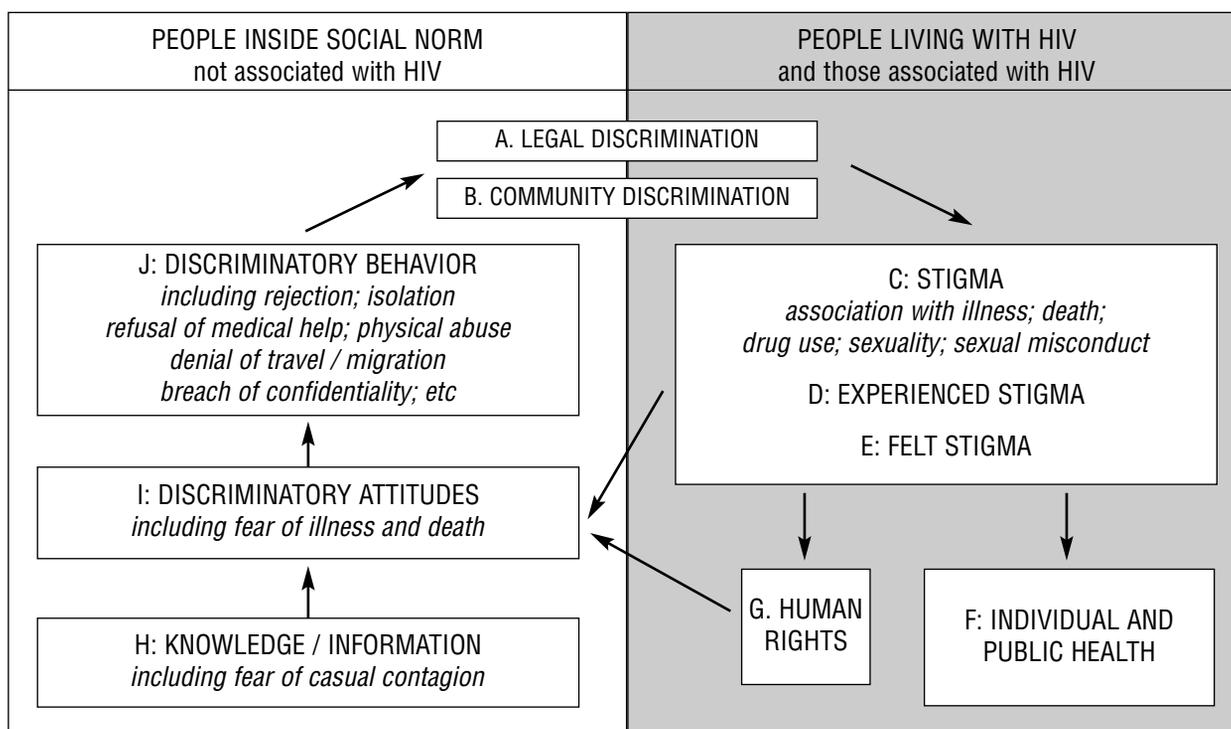
At domestic level, however, there often remains a considerable gap between this legal theory and the reality of individuals’ lives. In particular, the weakest members of society are both more vulnerable to HIV and HIV-related discrimination and have least recourse to the law to protect them from discrimination.

*A closer perspective*

Figure 3 confirms that HIV/AIDS-related stigma and discrimination is more complex than it at first appears. Some of the issues identified have already been discussed; others are analyzed in greater detail below. The primary conclusion to be drawn from the diagram, however, is that an appropriate response to the phenomenon depends on a clear understanding of what stigma and discrimination are, how they arise and what forms they may take.

**2.3. Measuring stigma and discrimination**

Until recently, while many studies have surveyed the beliefs, attitudes, behaviors and experiences of small groups of people, surprisingly little research had been undertaken into the extent of stigma and discrimination in society as a whole. Furthermore, there has been no standard measurement that allows stigma and discrimination to be

**Figure 4: Framework to measure HIV/AIDS-related stigma and discrimination**

compared in different communities and at different periods in time.

Attempts are now being made to standardize analyses of stigma and discrimination. Indicators to measure legal and community discrimination (components A & B in Figure 4) across a wide range of social settings, including health care, employment and the legal process, have been proposed by UNAIDS. (UNAIDS 2002c) Attempts are also being made to update a standardized survey of attitudes (component I in Figure 4). (UNAIDS / Measure, 2001) In Africa in 2001 a three-day consultation identified issues for a research agenda on that continent. (UNAIDS / HDN / SIDA 2001)

However, such surveys do not measure all aspects of the phenomenon. Ideally, a comprehensive survey of stigma and discrimination in a community would measure each component according to a standardized analysis and note its relationship to other components, as described in Figure 4. Such a survey, however, has yet to take place.

#### Framework components

##### A LEGAL DISCRIMINATION

*A review of existing and proposed legislation and policy and the extent to which it has been implemented*

##### B COMMUNITY DISCRIMINATION

*A review of discriminatory behavior and actions, as practiced by those within the social norm (J) and perceived by people living or associated with HIV (D), compared with the incidence of non-discriminatory behavior and actions*

##### C STIGMA

*A review of the negative (and positive) attributes associated with HIV/AIDS in the eyes of both the majority and those living with HIV*

##### D EXPERIENCED STIGMA

*A review of experiences of discrimination, compared with the incidence of non-discriminatory behavior and actions.*

##### E FELT STIGMA

*A survey of actions and inaction taken by people with HIV to prevent facing potential discrimination*

**F INDIVIDUAL AND PUBLIC HEALTH**

*An analysis of the impact of discrimination and stigma on individual and public health*

**G HUMAN RIGHTS**

*A survey of actions and inaction leading to violations of basic human rights and fundamental freedoms, protection of the human rights of people living with HIV/AIDS, and promotion and dissemination of the human rights norms that protect people living with HIV/AIDS*

**H KNOWLEDGE / (lack of) INFORMATION**

*A survey of people's knowledge regarding HIV transmission and the behaviors of stigmatized groups*

**I DISCRIMINATORY ATTITUDES**

*A survey of people's attitudes towards HIV/AIDS and people living with the virus*

**J DISCRIMINATORY BEHAVIOR**

*A survey of people's behavior towards HIV/AIDS and people living with the virus - noting the potential anomalies between self-reported behavior, observed behavior and behavior perceived by people living with HIV/AIDS.*

- Confusion between components
- Focus on self-reported knowledge, attitudes and experiences to the exclusion of other techniques, in particular observation
- Analysis of one component without linking that component to the overall picture
- Small samples (often under 100 people and / or restricted to one institution)
- Differing methodologies
- Similar methodologies but with details (such as questions on questionnaires) which vary considerably from author to author
- Surveys that emphasize negative experiences and give no indication of the extent of neutral or positive experiences
- Surveys published two or more years after they were undertaken
- Failure to take into account changing circumstances, such as increased access to antiretroviral drugs.

In practical terms, the most glaring deficiencies are:

- Discrimination or discriminatory attitudes or behaviors described as stigma
- Little or no analysis of the correlation between attitudes and behaviors
- Reliance on self-reporting rather than observation
- Little or no link between reported attitudes from those within the social norm and reported experiences from people living with HIV/AIDS
- Emphasis on the negative.

**2.3.1. Existing surveys**

In an attempt to provide a comprehensive analysis of the different components of stigma and discrimination, this review identified, through health libraries and similar resources online and through non-specialist resources such as Google, a range of studies from different countries between both the general population and health workers. (See Bibliography)

A pattern was identified whereby some components of stigma and discrimination were studied far more than others. Those that were most studied include components H and I (knowledge and attitudes in the general community) and component D (experiences of stigma and discrimination among people with HIV/AIDS). Even in those areas, however, inconsistencies and defects prevented development of an accurate standard with which to compare different communities or different periods. These inconsistencies and defects include:

Therefore, the conclusion that this review draws is that while HIV/AIDS-related stigma and discrimination are clearly widespread, it is difficult to accurately measure the extent of the problem. Because there is not space in this report to examine each of the components described above, the rest of this section focuses on the knowledge and attitudes of those inside the social norm (components H and I) and the experience of stigma of those outside it (component D).

### 2.3.2. Public knowledge and attitudes

The United States, where the disease was first identified over twenty years ago, has seen both some of the most intensive HIV/AIDS-related prevention and information campaigns and the most comprehensive surveys of stigma and discrimination. Despite the efforts of the former, the latter reveal that misinformation about the disease and discriminatory attitudes persist in a significant proportion of the population.

While recent surveys confirm that education campaigns have increased the public's awareness of how HIV is transmitted, a significant percentage of the population still does not have a clear idea as to how the virus is not transmitted. In a 1999 survey of 669 people, 50% of respondents believed that HIV could be contracted through sharing a glass with, or from a sneeze or cough from someone with HIV/AIDS, while 40% believed the virus could be contracted from public bathrooms. (Herek et al 2002) In 2000, a survey of 5,641 people showed 40% or respondents believing that HIV could be transmitted through sharing a glass and 41% believing that transmission could result from a cough or sneeze. (CDC 2000)

Surveys of attitudes confirm that in the United States at least, the majority of the population does not stigmatize people with HIV/AIDS. However, approximately one in six of those interviewed in 1999 believed that the names of people with HIV should be published; one in five experienced fear when interacting with an individual with the virus; one in four believed that people who inject drugs or have sexually risky behavior “deserve to have been infected”; 29% would avoid buying from a local store if they learned that its owner had HIV; and 30% would be uncomfortable with the idea of a child with HIV/AIDS attending the same school as their son or daughter. (Herek et al 2002) The 2000 survey found that almost 19% stated that persons who acquired the disease through sex or drug use had “gotten what they deserve” and that men, white people, older people, the poor, the ill and those with less education were more likely to attribute stigma. (CDC 2000) High though these

figures are, overt expressions of discrimination declined in the USA throughout the 1990s, with support for the most coercive responses to the disease, such as quarantine, at very low levels by 1999. (Herek et al 2002)

Studies from other countries reveal a similar picture in that knowledge and awareness appears highest where there has been most publicity. A survey of 6,777 people in China in 2002 revealed that only 7% of city residents and 17% of town residents were unaware of HIV/AIDS. A higher number were uncertain how the virus is transmitted (26.6% city residents; 37.5% town residents) or did not know that condoms offered protection (68.5% city; 76.5% town). Discriminatory attitudes were high: only 41% of city residents and 31% of town residents believed people with HIV should be allowed to return to work, although that percentage diminished with education and among the 26-35 year old age group. (Futures Group 2002) In Singapore a survey of 413 young people confirmed widespread knowledge about how HIV can be transmitted but uncertainties over possible transmission through casual contact. (Lim et al 1999)

### 2.3.3. Experiences of people living with HIV/AIDS

What is the exact link between misinformation and discriminatory attitudes in the general population and experiences of people living with HIV/AIDS? Does everyone with a discriminatory attitude consistently behave in a discriminatory manner towards people with HIV/AIDS? If 25% of a given population hold negative attitudes and behave accordingly, does that mean that only 25% of people living with HIV/AIDS experience discrimination, or that all people with HIV/AIDS experience discrimination, but only 25% of the time? Or, as is most likely, is the reality more complex than can be conveyed in percentages?

Unfortunately, that information is difficult to ascertain. Ideally, a direct comparison could be made between attitudes and behavior by surveying not only a population group but also the people living with HIV/AIDS that they come into contact with. In a sample taken from the general popula-

tion, however, this is almost impossible. And even if that obstacle were overcome, behavior remains the most difficult component of stigma and discrimination to measure, because it either takes place in private or is modified in the presence of observers.

In place of observing behavior, therefore, most analyses survey the extent to which people living with HIV/AIDS report being subject to discrimination. Surveys developed in Chile (Vivo Positivo 2002), India (UNAIDS 2002a) and Uganda (UNAIDS 2002a) report widespread and severe discrimination against people living with HIV/AIDS. This occurs in a variety of settings, including the family, workplace, the community and health care settings.

The primary defect of such surveys is that they are almost all anecdotal and focus on negative experiences. An accurate picture of experienced discrimination depends on a statistical analysis that would include information such as: (a) the percentage of people living with HIV/AIDS who have ever experienced discrimination, (b) the number of times they have experienced discrimination, (c) the sources and (d) impact of that discrimination (for example, an offensive comment from a passing stranger may have less impact than repeated discrimination at work or in a hospital), and – most importantly, for an accurate picture – (e) comparison with incidences of neutral or positive behavior.

Furthermore, surveys would take into account the availability of antiretroviral drugs. These reduce the incidence of opportunistic infections and significantly prolong active life for people living with HIV/AIDS. Anecdotal evidence suggests that the

resulting disassociation of the disease and death has begun to reduce the extent of discrimination and, potentially, the depth of stigma in communities where medication is widely available. And irrespective of the availability of antiretroviral therapies, there is evidence that improved health leads to fewer incidents of stigma and discrimination. (Heckman et al 1997)

#### **2.3.4. Information missing**

There is no doubt that HIV/AIDS-related stigma and discrimination is real, extensive and frequently causes considerable distress to those affected by it. In its extreme form it can lead to physical violence and murder. It harms individual and public health by discouraging those who are at risk, including those who do not know they are at risk, from seeking counseling, information and treatment.

But we do not know the extent of stigma and discrimination. We do not know whether it is the norm for every individual living with HIV/AIDS or whether or how much some groups or individuals are more affected than others. Nor do we know how much the situation is changing.

Such information may not be essential – responses to stigma and discrimination should not depend on whether a minority or majority are affected or whether it is less prevalent than before – but without understanding of the true extent of the phenomenon, we cannot accurately measure the effectiveness of programs that seek to reduce it.