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BREAKING THE CYCLE:
STIGMA, DISCRIMINATION, INTERNAL STIGMA, AND HIV

STIGMA, DISCRIMINATION, AND HIV IN 2006

During the first few years of the 21st century, discussion of HIV and AIDS shifted to a greater focus on related issues, such as stigma and discrimination, gender, and development. Recognition of the significance of HIV-related stigma and discrimination has put them at the forefront of strengthening effective responses to HIV. At long last, academics, researchers, activists, service providers, and people living with HIV are beginning to understand and articulate the consequences of addressing (or not addressing) and measuring HIV-related stigma and discrimination. This paper reviews the present understanding of HIV-related stigma and discrimination as they relate to vulnerability, and suggests approaches for stigma reduction. It explores and examines what constitutes HIV-related stigma and discrimination, what effects they have on behavior and HIV responses, and what we can do to reduce them.

> *That doctor did not know much about what HIV was. I arrived at the appointment and he didn't touch me. I sort of expected that kind of reaction. Besides, physically I felt so bad that how could I fight with him. He sent me to one of the hospitals that had quite a few AIDS patients and the same thing happened with the nurses. One can't help but notice, by the way that they look at you, that you're being judged… HIV is a big problem in our country because there is still a lot of ignorance related to the theme. Discriminatory attitudes and rejection of those living with HIV persist; moreover health services are not really adequate. There is so much to do so as to take this disease seriously… There are still many people with erroneous ideas about what HIV signifies. Sometimes I get so angry that people can be so insensitive. It is really troubling that people at risk of infection think that AIDS is something far away; that it could not happen to me.*
>
> *Eugenio, diagnosed HIV positive in 1992*

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THE HISTORY OF UNDERSTANDING OF HIV TRANSMISSION

Over the past 25 years, we have seen an evolution in our understanding of HIV (the virus), of the AIDS epidemic, and of the factors involved in HIV transmission, prevention, and care. When AIDS was first detected, it was closely associated with certain sub-populations; epidemiologists identified and labeled them as "risk groups." The enduring responses to this labeling have been systematized stigmatization and distancing. People who did not identify with these groups did not see themselves at risk; those that did identify with these sub-populations, or were deemed to be part of them, were ostracized and branded as perpetrators of infection. At that time, the source of an immune system breakdown was unknown and responses were based primarily on fear and conjecture. When HIV was detected and deemed to be the source of infection, the enormous anxiety associated with the unknown was somewhat diminished. Over time, a new understanding of transmission arose and was defined as "risk behavior." Ideas such as protected sexual activity and choice of sexual partners became part of our collective appreciation. Attention was shifted from persons to acts.

Through the 1980s and into the 1990s, as a result of behavioral studies, new concepts of risk factors came into play and led to the reconceptualization of HIV regarding "risk situations." This insight took into consideration such factors as the influence of power relations, the use of alcohol, the availability of preventive commodities (e.g., condoms), and the probability of encountering a partner who was infected. In turn, this new awareness, combined with ideas of health promotion and human rights, caused us to look at HIV and AIDS in a whole new light: that of "vulnerability" to infection. This was not so much a revolution in thinking, but a progressive appreciation over time.

VULNERABILITY AND HIV

Vulnerability is a concept based on notions of "susceptibility to attack or to being wounded." It includes aspects related to risk, which in turn are related to the "source of danger," the possibility of incurring misfortune, or in this case, the probability of becoming infected or falling ill. By combining factors from an understanding of sociology and anthropology with those from psychology and epidemiology, we have a clearer understanding of vulnerability. It can be explained, for example, by combining three spheres of interaction: Society, self, and situation.[1] Each sphere is related to and reinforced by the other spheres.

Society refers to the underlying factors that would influence self and situation, including social, economic, cultural, and political aspects; access to prevention and care services; community support networks; sources of information; and, importantly, stigma and discrimination. *Self* refers largely to the capacity of an individual to cope with different or difficult circumstances. This would include attributes and characteristics such as knowledge, experience, self-esteem, self-acceptance, and life skills. These are the factors that a person would bring to bear on any given situation of risk. *Situation* refers to the actual circumstances and conditions related to an event or occurrence. This might include the act undertaken, use of alcohol or drugs, the state of mind of an individual at that point (being depressed, desperate, or hiding), power relations in an encounter, immediate access to prevention commodities, and the prevalence of HIV in the population or the probability of an encounter with someone who is HIV positive. Combining these three interconnected spheres presents a much better sense of vulnerability or the factors related to a person's susceptibility to infection or to getting sick (see Figure 1).

STIGMA AND DISCRIMINATION: EARLY CONCEPTUAL MODELS

Stigma and discrimination are recognized as two key factors that need to be addressed to create an effective and sustained response for HIV prevention, care, treatment, and impact mitigation. The effects of HIV-related stigma and discrimination can be felt on many levels: individual, family, community, programmatic, and societal. They represent obstacles such as preventing individuals from being tested; preventing persons from recognizing that they or family members are HIV positive; inhibiting people from seeking care, support, and treatment; causing people to mislead others; impeding people from using protection in intimate relations; preventing quality care and treatment; increasing social inequities; hindering the access of people living with HIV to housing, education, employment, and mobility; negatively affecting quality of life; and, eventually, leading

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[1] This is the author's adaptation of work outlined by F. Delor and M. Hubert (2000).

FIGURE 1. THE CYCLE OF VULNERABILITY: SOCIETY, SELF, AND SITUATION

to increased transmission, morbidity, and mortality.

Stigma and discrimination are interacting aspects that are common in all walks of life. While stigma refers to the realm of attitudes and perceptions, discrimination relates to action and behavior. The word “stigma” has Greek origins referring to the marks of physical deformities of foreigners or persons deemed inferior. Christians gave this word a twist by using it to refer to the physical indications of the divine spirit. In modern times, stigma has been defined as “an undesirable or discrediting attribute that an individual possesses, thus reducing that individual’s status in the eyes of society” (Goffman, 1963). It is a labeling of an individual or group as different or deviant.

In the late 1980s and into the 1990s, there was a move to take a second, more detailed look at the global HIV epidemic that, until that point, seemed to be very different in different areas of the world. This led to a clear conclusion: The majority of those affected by HIV had one thing in common—they were in some way or another marginalized within society. This recognition caused Jonathan Mann, then head of the Global Program on AIDS at the World Health Organization (WHO), to note that there were really three phases of the epidemic: the epidemic of HIV transmission, the epidemic of AIDS, and, finally, the epidemic of stigma, discrimination, and denial.

UNAIDS, recognizing the vital importance of reducing HIV-related stigma and discrimination and addressing HIV within a human rights framework, made this the theme of the World AIDS Day Campaign for both 2002 and 2003. Parker and Aggleton[2] provided a basis for action in this campaign by stressing that stigmatization is a *process* that works to produce and reproduce power relations, and that HIV-related stigma reinforces existing social inequalities. Their framework outlined four priority issues for action: 1) improved understanding of stigma and discrimination, where they come from, and what they do; 2) increased appreciation of links to broader existing inequities and injustices; 3) better understanding of the complex stigma- and discrimination-related issues that precipitate the epidemic; and 4) clear identification of objectives for results. As a response to the many challenges outlined above, the POLICY Project, funded by the U.S. Agency for International Development (USAID), undertook projects in two countries to foster better understanding of and responses to HIV-related stigma and discrimination.

POLICY’S STIGMA MITIGATION INITIATIVES: MO KEXTEYA AND SIYAM’KELA

Mo Kexteya: Náhuatl language of Aztecs, connotes similarity, comparability, and likeness or “to appear,” “to come out,” or “to change”; emphasizes visibility and empowerment.

Siyam’kela: Nguni word, meaning “we are accepting” or “together we stand”; emphasizes the need for unity and compassion.

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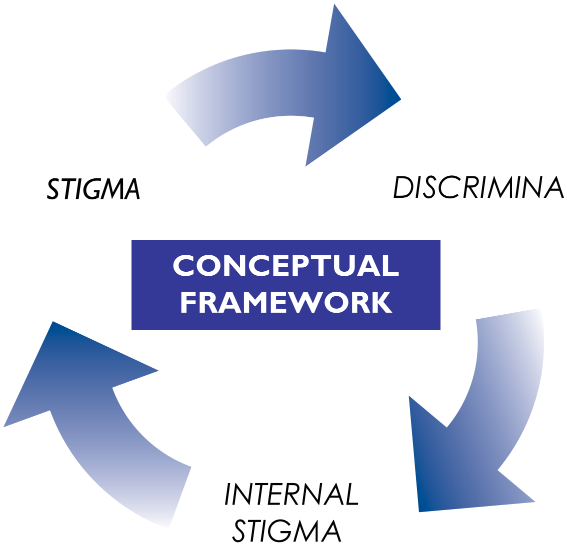
[2] See Parker et al. (2002) and Parker and Aggleton (2003).

In late 2002, the POLICY Project and its partners initiated pilot projects in Mexico (called Mo Kexteya) and South Africa (called Siyam'kela) to systematically contribute to the reduction of HIV-related stigma and discrimination. These countries were chosen in part because they represented very different faces of the pandemic. In South Africa, there is a high-prevalence, generalized epidemic with alarming effects on all walks of society, but especially on young heterosexual women. Mexico, like most countries in Latin America, is experiencing a concentrated epidemic that primarily affects men who have sex with men (MSM). The initial formative research phase looked closely at stigma and discrimination for people living with HIV, as well as focusing on health and government services, the legal and policy environment, faith-based communities, and the media. This phase set out to explore the situations of stigma and discrimination in both countries, to increase the understanding of their causes and effects, to develop policy and program guidelines for their reduction, and to identify indicators for measuring HIV-related stigma and discrimination, as well as evaluating the impact of mitigation strategies.

FIGURE 2. A CONCEPTUAL FRAMEWORK: STIGMA, DISCRIMINATION, AND INTERNAL STIGMA



POLICY'S REVISED CONCEPTUAL MODEL

To better understand HIV-related stigma and discrimination, one needs to break them down into their interrelated components. Building on the work of Parker and Aggleton and others, and synthesizing the results of the formative research from the two country studies, three key components emerged as part of a cyclical continuum: stigma, discrimination, and internal stigma. Stigma causes discrimination; discrimination leads to internal stigma; and internal stigma, in turn, reinforces and legitimizes stigma (see Figure 2).

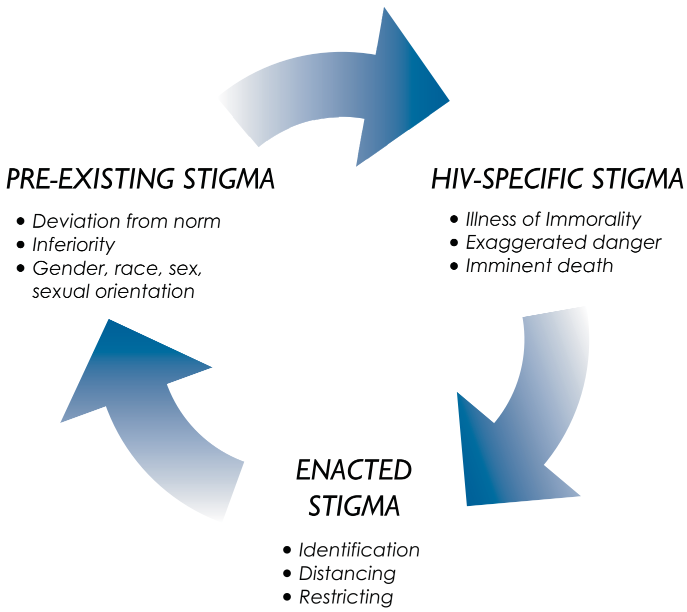
Stigma lies primarily in the realm of perceptions and attitudes, such as a negative attribution to a group or individual. Discrimination moves into acts and behavior—a differential treatment based on those negative attitudes. Internal stigma is the result of the internalization and acceptance of the lived situations of stigma and discrimination that a person or group endures over time. Each of these components can, in turn, be subdivided into vital elements, defined in the diagnostic phase. Each component is separated into three parts: the first describing key concepts and situations; the second describing recurring themes and frameworks; and the third describing results and practice.

Stigma

In the studies in both South Africa and Mexico, stigma associated with HIV could be seen as consisting of three categories: pre-existing stigma, HIV-specific stigma, and enacted or tangible stigma (see Figure 3). These categories are overlapping and interrelated—they do not act as isolated elements, but form a continuum which build on and buttress the other categories.

Pre-existing stigma was found to be a vital factor for understanding the stigma surrounding HIV. The recurring characteristics of pre-existing stigma included negative attitudes toward sex and illicit drug use, as well as questions of gender, race, sexual orientation, and class or economic status. Pre-existing stigma in all cases seemed to focus on issues of deviation from the "norm" (difference), inferiority, or weakness, as well as people trying to come to terms with the unknown (including the fears, myths, and prejudices that accompany that process). In South Africa, AIDS was perceived as a poor African woman's disease, while in Mexico it was equated with homosexuality.

FIGURE 3. ELEMENTS OF STIGMA



The recurring aspects of **HIV-specific stigma** included: the illness of immorality, imminent death, and exaggerated sense of danger. The illness of immorality derives from the fact that AIDS is considered “dirty” and is closely tied to pre-existing stigma. In Mexico, for example, a clear equation for most of the perceptions of society related to “lifestyle and risk” became evident: AIDS = homosexuality = bad = death. An exaggerated sense of danger was often related to a lack of information or misinformation about HIV and AIDS, and a heightened, sometimes irrational, sense of perceived risk.

Enacted stigma describes a process that moves beyond perceptions and attitudes and into actions. It consistently followed a similar three-step pattern: identify those infected, create a distance between oneself and “them,” and restrict or exclude “them.” The specifics of this pattern changes slightly from case to case, country to country, but the overall pattern remains the same. Testing followed by violation of confidentiality was a common example of enacted stigma. Labeling or marking people living with HIV, avoidance, isolation or segregation, and differential treatment or prohibiting actions were also recurring aspects. Unconscious actions and institutionally sanctioned actions are often part of enacted stigma.

Discrimination

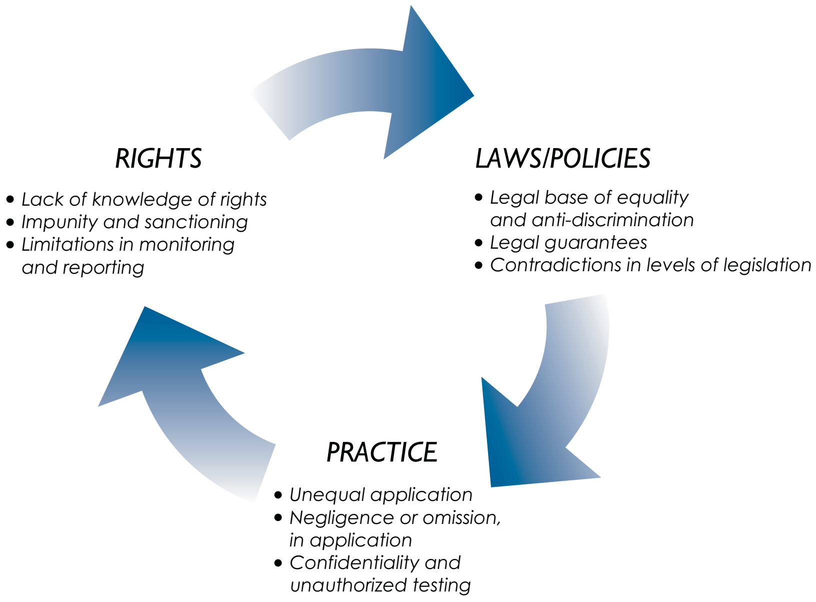
In the formative research phase, the projects in Mexico and South Africa identified three recurring categories related to discrimination: law and policy, application or practice of laws and policies, and human rights (see Figure 4). While discrimination exists in all walks of life and involves dividing into categories and making choices, common usage refers to action in relation to a legal or ethical referent. Discrimination is differentiated from, yet on a continuum with, enacted stigma because of its severity and in relation to international accords, laws, and policies.

In terms of **human rights**, the projects noted that there was a general lack of knowledge about what rights were, what rights one had, and what recourses one had for redress in relation to violations of rights. This was true for people living with HIV, groups vulnerable to HIV infection, health service providers, media personnel, and even lawyers and parliamentarians. In both South Africa and Mexico, this, in turn, was compounded by a history of impunity and a lack of sanctioning of those who failed to comply with the law.

In the case of the **laws and policy** in South Africa and in Mexico, the formative research found that there was a solid base for combating discrimination within the constitution, international treaties and accords, and existing laws and policies. A firm legal base is of vital importance for setting standards from which human rights related to HIV can be promoted

> ***“Living with HIV causes confusion related to death and sexuality—so people come and tell you ‘you’re gonna die’ and you have to live with that stigma… I have not been denied services yet, but I live with the stigma of differentiated treatment.”***
>
> *Eugenio, diagnosed HIV positive in 1992*

FIGURE 4. ELEMENTS OF DISCRIMINATION



and individuals living with HIV can be protected. This foundation includes both elements of equality and anti-discrimination. In Mexico and South Africa, there were, moreover, many cases of guaranteed access to health services, including treatment and the means of redress when rights were violated. In a few cases, areas of "legalized" discrimination exist—laws that are contrary to the constitution or international treaties. This was most obvious, for example, in the case of being able to discharge HIV-positive military personnel without recourse in Mexico and in many other countries.

Practice, however, was another story. Negligence and omission were common in the application of laws, policies, and regulations, including unequal application and loss of confidentiality. There were cases of compulsory testing, for example, that clearly contravened written policies.

Internal Stigma

While the need to confront internal stigma is universal for those infected and affected by HIV, the individual manifestations of feelings, emotions, and reactions can vary greatly from person to person. Internal stigma is a complex process that is affected by one's sense of self, as well as external and physical influences. In response to experiencing stigma, people living with HIV may adopt protective actions that, in turn, tend to reinforce and legitimize internal stigma (Brouard and Wills, 2006). Based on findings from the South Africa and Mexico projects, internal stigma—the internalization or acceptance of experienced stigma—is conceptualized as a cycle of three significant categories: the experiences of context, self-perception, and protective action (see Figure 5). The projects focused on the internal stigma of people living with HIV; however, the case can be made for extrapolating these findings to marginalized groups that are vulnerable to HIV infection.

Experiences of context include the physical and environmental situations in which people live. The projects found that there were several interacting elements that led to an overall sense of loss of control for people living with HIV. These elements included: the level of misinformation, being subjected to denigration and negative prejudices over time, economic and social pressures (e.g., anxiety about losing a job due to one's HIV status and concerns about how this would affect access to treatment), and physical deterioration of one's health (e.g., internalized stigma was worse when people living with HIV experienced visible manifestations of the disease, such as weight loss or opportunistic infections).

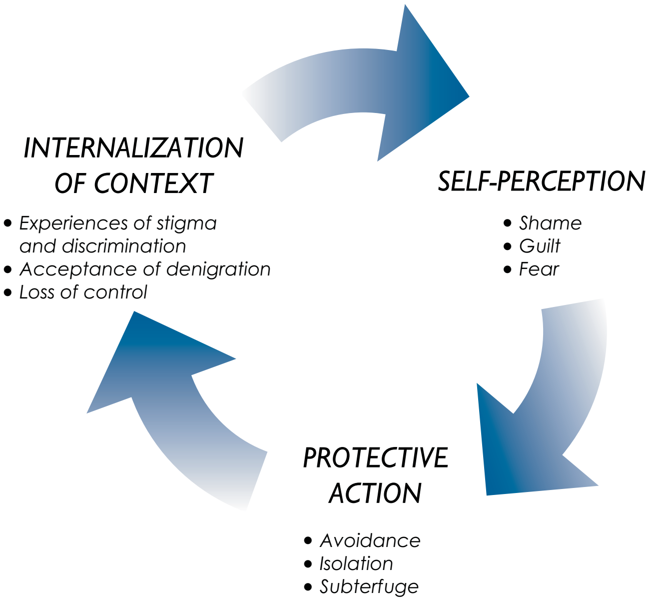
In the area of **self-perception**, the formative research phase uncovered several recurring elements; in particular, shame and guilt were extremely common, as was a sense of self-blame. Added to these emotions were many deep-seated fears that included the following: fear of dying; fear of hurting or infecting others; fear of being discovered; and fear of causing pain, disappointment, or suffering to family members.

> ***"It took a lot of effort to learn to live with HIV and keep on with my life."***
>
> *Juan, living with HIV since 1997*

Given the experiences of context and the sense of self-perception, people living with HIV adopted different means of **self-protective action**. Avoidance and self-exclusion, for example, included such things as avoiding making long-term plans, avoiding activities in general, and avoiding seeking health services or treatment. Isolation and self-withdrawal meant that HIV-positive people tended to keep to themselves, avoiding social activities (even family activities) and intimate encounters and relationships. Subterfuge and denial were common: hiding or misleading others, for example, as to one's serostatus, sexual orientation, or livelihood.

The three categories described above interact in a cycle of internal stigma, each feeding on or building on the effects of the others. For people living with HIV who are from marginalized or stigmatized populations, this internal stigma was often exacerbated.

FIGURE 5. ELEMENTS OF INTERNAL STIGMA



VULNERABILITY AND STIGMA

To understand the relationship between stigma and discrimination, one can look at different lives and contexts taken from our studies and analyze them within the context of vulnerability. If we examine, for example, three case studies—a single mother living with HIV in the developing world; a young man who yearns for same-sex intimacy, but is in a conservative environment; and a family with a member who is HIV positive in a rural community—we can get a clear image of the causes and consequences of stigma in a context of vulnerability.

- A young woman lives with her two small children. She is HIV positive, which was discovered when she had her second child; her children have not yet shown signs of illness. She had limited antiretroviral (ARV) treatment during the birth of her child and has had limited and inconsistent access to treatments since. When she had medication, she hid it from everyone and was often in public situations where she did not take her pills. She has no access to specialized health services without costly travel, so she has had to go to a local clinic. Word has gotten around the small city where she lives that she is HIV positive, and her family is pressuring her to leave, in both subtle and overt ways. She is given enough money for one-way passage and is left with her children to make her own way. Her health is sometimes precarious; money for feeding her family is scarce; and she has to find all sorts of means to feed them. She finally finds a clinic with free access to drugs and laboratory services, but the regimens do not seem to work, as she shows clear signs of disease development.

- The young MSM lives in a conservative society of gender inequality and high levels of intolerance and hatred towards homosexuals. There are pressures to follow social norms regarding education, employment, and marriage. He does not know of or have access to a health professional with accepting attitudes, so this young man has no one with whom to talk about his sexuality. His life is filled with guilt for his yearnings, shame for being who he is, and a dread of being truly alone and cut off from his family and friends. He remains isolated much of the time, feels forced to hide and constantly deceive others but, in moments of strong depression and alcohol consumption, has hidden sexual adventures. These adventures are fleeting moments of desperation; condoms often are not available and this young man feels he cannot carry one with him due to the suspicion it might raise because he does not use a condom with his wife.

- The mother of a large family living isolated in a farming community discovers that her son is HIV positive because the community nurse thought it her duty to warn the family. Sufficient funds to feed and clothe the family are dependent on a small family business, but she fears that the son's HIV status will keep customers away and that they will be isolated. She thinks that there is nothing to do, and that she must first think about her healthy children. Also, she fears the reaction of her sometimes violent husband, so she sends the son away. He leaves and slowly makes his way to a large city to find work and health services. The route is long and arduous and he is very ill when he arrives in the city. The hospital refuses him entrance. With no one to care for him, he sleeps wherever he can and begs for scraps of nourishment. Finally, a community health center takes him in, but by this time he needs constant care and treatments for multiple infections.

These fictive renditions of real-life situations tell a clear story of the consequences of stigma and discrimination for effective care, treatment, and prevention responses to HIV and AIDS (see Table 1). With the multiplication of these types of stories and increasing numbers of infections, they also tell the story of the consequences of not working to reduce HIV-related stigma and discrimination.

POLICY CONSIDERATIONS

Policy considerations in relation to addressing and reducing stigma and discrimination are varied, but all are of vital importance (see Table 2). If we are to deal successfully with HIV in our societies, governments and community leaders need to reduce stigma and discrimination; doing so will decrease HIV transmission and improve the quality of life for those living with and affected by HIV.

In developing strategies for stigma reduction, POLICY and its partners have identified five fundamental policy guidelines and their particular applications to HIV-related stigma and discrimination:

1. The importance of a strong foundation of evidence-based knowledge of HIV-related stigma and discrimination.

Any successful response to stigma and discrimination needs to be based on a clear understanding of these phenomena and should be in line with available evidence. This includes being sure that people clearly understand what HIV is, how it is (and is not) transmitted, and how it is treated. It also means that people undertaking stigma reduction strategies or those targeted by them need to have a clear idea of what stigma and discrimination are, how they affect HIV, and what can be done to counter them. Finally, although the conceptual framework above describes the essential elements of HIV-related stigma and discrimination, each specific situation will be slightly different. Successful stigma reduction strategies need to be based on a clear and insightful appreciation of the specific local contexts and conditions and must build on lessons learned from past experience and from others. Some of the essential tools will be situation and response analysis and

TABLE 1. VULNERABILITY AND STIGMA

	Society	Self	Situation	Consequence
Young MSM in conservative society	▪ Homophobia ▪ No accepting health services ▪ Social pressures	▪ Guilt ▪ Shame ▪ Fear of being alone	▪ Subterfuge ▪ Hidden sexuality ▪ Depression and alcohol	▪ *Inconsistent condom use* ▪ *Marriage to mask hidden life* ▪ *Intimacy and desperation*
Single mother living with HIV in the developing world	▪ Stigma in health services ▪ Limited access to good services ▪ Inconsistent treatment access	▪ Guilt of condition ▪ Shame to acknowledge publicly ▪ Fear for family	▪ Rejection by family and friends ▪ Declining health ▪ Depression	▪ *Problems with adherence and risks of resistance* ▪ *Late treatment* ▪ *Economic precariousness and desperation*
Family with a person living with HIV in a rural community	▪ Stigma in society ▪ No access to specialized health services ▪ Interdependency in community	▪ Shame ▪ Misunderstanding ▪ Fear of infection	▪ Rejection by family ▪ Migration to urban center ▪ Social isolation	▪ *Increased need for health services* ▪ *Breakdown of traditional care structure* ▪ *Increased burden on health services*

TABLE 2. POLICY CONSIDERATIONS

	Vulnerability Issues	Policy and Programming Implications
SOCIAL	▪ Such a thing as similar vulnerability patterns in sub-populations affected by HIV: Group vulnerability ▪ High levels of stigma and discrimination which have significant consequences on service delivery ▪ Lower levels of solidarity ▪ Little visibility other than stigmatizing negative press ▪ Negligible voice in social and political affairs and decisionmaking	▪ Confidentiality ▪ Public acceptance ▪ Policy and programs that are inclusive of rights and treatment of marginalized sub-populations ▪ Sanctioning for violations of human rights, laws, and regulations ▪ Clear, accessible systems for receiving and dealing with complaints ▪ Promotion of "you can complain: we will listen" ▪ Building social capital in communities and families
SELF	▪ Normalization and acceptance of stigma and discrimination ▪ Discomfort with self ▪ Resignation and denial ▪ Hiding and fear of being alone ▪ Information access and acceptance	▪ With acceptance: rights and responsibilities ▪ Building self-esteem and individual social capital ▪ Promotion of "I am good" ▪ Capacity building ▪ Interaction and communication with others ▪ Graphic, clear messages and options
SITUATION	▪ Risk practices, and "balancing" risks ▪ Access to prevention commodities and tools ▪ Love and companionship as a risk factor ▪ Depression, search for diversion, and pleasure ▪ Sex, affection, and sharing intimacy	▪ Risk assessment, risk management ▪ Access to quality condoms and lubricants ▪ Partners, practice ▪ Pleasure in life and living ▪ Acceptance, communication, negotiation

diagnosis that will assist in the identification of populations key to specific epidemic dynamics, of particular stigma issues, as well as priority needs, resources, and available options. Some key aspects include the clarification of the difference between HIV and AIDS and the ability to understand the specifics of vulnerability and realistic risk assessment in a given environment and situation, as well as a focus on affirming life rather than on impending death.

2. Applying simultaneous, multi-targeted strategies in any given situation.

To effectively tackle stigma and discrimination, strategies need to deal with both consequences and causes. Although we cannot presume to change the basis of modern society, we need to be able to address the underlying causes and pre-existing elements of stigma: social and gender inequality, poverty, and prejudice.

One cannot hope to reduce HIV-related stigma in a society such as Mexico, for example, without addressing homophobia. In South Africa, gender and economic inequality need to be taken into account.

Virology has shown us that, to contain HIV in the body we need to attack it at different points in its reproduction cycle. This lesson also is true for stigma and discrimination strategies. Effective strategies should deal simultaneously with different elements of the stigma-discrimination-internal stigma cycle; this might involve a multifaceted response that includes targeting information and sensitization campaigns, improving the socio-political and legal environments, mobilizing communities, and strengthening the self-esteem and social capital of people living with HIV, as well as increasing the visibility of those infected and affected by the epidemic. A coherent program of

STIGMA REDUCTION POLICY GUIDELINES

1. *Building on evidence-based knowledge of HIV-related stigma and discrimination*
2. *Applying simultaneous multi-targeted strategies in any given situation*
3. *Utilizing a gender focus throughout strategies*
4. *Incorporating a rights-based approach in comprehensive responses*
5. *Empowering individuals and communities to sustain any stigma reduction strategy*

reduction of HIV-related stigma and discrimination should address all three levels of stigma, discrimination, and internal stigma.

3. Utilizing a gender focus throughout strategies.

HIV-related stigma and discrimination are closely tied to the gender-based roles, capacities, and potentials in each society. Gender refers to a combination of attributes: symbolic, social, political, economic, legal, and cultural attributes that are assigned to a person according to his or her sex. To reduce stigma and discrimination, we need to look closely at the underlying elements of the construction of masculine and feminine roles and identities. Sexual relationships are not separate or distinct from the power relationships and gender dynamics that exist in societies, and between men and women. This holds true for same-sex relationships which often adopt and adapt the power relationships found in the general society.

Included in a gender focus is the need to address economic opportunities, independence, and stability for women and youth. Women—and especially young women and women living with HIV—need to be empowered and to have their leadership qualities developed. A gender focus also includes such aspects as increased participation of institutions and of men in care programs and stigma reduction related to HIV.

4. Incorporating a rights-based approach in comprehensive responses.

Vital to any successful response to HIV is a response based on upholding human rights for all citizens. Such a response needs to include an understanding of human rights for all involved, including people living with HIV, persons affected by or vulnerable to HIV, and health professionals. There needs to be a solid legal basis for promotion and protection of human rights. Sound policies should not only be adopted in public and private institutions, but also need to be promoted, enforced, and applied (and non-application sanctioned). The common good and public health goals rarely are contradictory to rights, social justice, and human compassion. Moreover, asking for social responsibility requires attributing basic human rights to all.

A human rights approach to reduction of stigma and discrimination should include assistance in seeking legal recourse for persons whose rights have been violated. It also should include building a response to HIV around a human rights framework based on a stigma/discrimination analysis, a sound legal and policy basis, and a monitoring and measurement process to highlight accomplishments and challenges.

5. Empowering individuals and communities to sustain any stigma reduction strategy.

Empowerment—the process of helping to foster capacities of people to look after their own needs—constitutes the base of an effective response to stigma and discrimination. It can be an individual as well as a group process. It might include strengthening skills and knowledge, building self-acceptance and social capital, improving the socio-political environment for healthy change, and enhancing elements of organizational skills development. Empowering individuals and communities includes helping them acquire advocacy and communication skills. It is a process that helps ensure that those directly affected by HIV are integrally in-

> ***"We have to keep going, to fight harder and harder. If civil society is weak, the government should act. Besides strengthening AIDS organizations, we have to develop partnerships with other groups like cancer or diabetes in order to work together... We have to find new ways to keep up the fight because with the advances of science and the changes in ways of understanding this disease, there are changes in the way that infected persons are treated... We can't let down our guard only because there are treatments that prolong our life."***
>
> *Omar, living with HIV since 1986*

volved in decisionmaking processes, as well as in planning and implementing diverse strategies.

PROGRAM CHALLENGES

Programs for reducing stigma and discrimination should take into account some vital pointers so as to make the best of limited resources. Some suggestions include:

1. Set clear objectives for desired outcomes and change that focus on specific needs and priorities of stigma reduction in any given situation.

The overall framework for understanding stigma and discrimination presented above provides a basis for identifying program objectives and activities. Each context, however, will necessitate a situational diagnostic to identify needs and to determine what specific strategies or priorities are required, and perhaps how this framework might be adapted. Programming should be developed in terms of priorities, as well as the available or potential resources and organizational capacities.

Clear and precise objectives need to be set according to the changes a program wishes to bring about. These objectives need to be based on clear understanding of HIV, AIDS, stigma, and discrimination. The objectives of any program should address a range of issues related to factors that drive stigma, discrimination, and internal stigma. Addressing stigma and discrimination must be planned carefully to be effective; simply recognizing their importance is not sufficient. Stigma and discrimination reduction takes planned, active initiatives.

STIGMA REDUCTION POLICY GUIDELINES

1. *Setting clear objectives for desired outcomes and change that focus on specific needs and priorities of stigma reduction in any given situation*
2. *Addressing consequences, causes and impact of HIV-related stigma*
3. *Employing effective measurement and documentation in program plans*
4. *Ensuring that programs complement work done by others, and help to foster a comprehensive response*
5. *Building on existing programs*

Table 3 shows the breakdown of an example from Mexico on how objectives and strategies were developed based on a situational analysis of HIV-related stigma and discrimination.

2. Address consequences, causes, and impact of HIV-related stigma.

While stigma permeates all aspects of human social life, it will never be an easy element to eliminate. HIV-related stigma and discrimination will continue to wreak havoc on effective responses to the epidemic if their causes are not addressed. Addressing the roots of stigma and social inequalities also will have composite effects on health care, health service use, and health in general. At the same time, one cannot simply ignore the direct consequences and overall impact of stigma and discrimination.

Simply “raising awareness” will not reduce stigma because raising general awareness does not address the values and morality issues that feed people’s perceptions. Raising awareness, however, can help people to recognize the importance of stigma reduction work and its potential benefits.

A coherent response will deal with stigma and discrimination, and with mitigating their effects on people’s lives and health.

3. Employ effective measurement and documentation techniques in program plans.

To determine if programming is having the desired effect on stigma and discrimination, one needs to have a monitoring and evaluation plan in place. This requires a determination of the appropriate indicators that will help with measurement and with the development of simple, effective monitoring systems. Documenting and sharing failures, successes, and challenges will provide much needed guidance to others undertaking similar work. Measurement should include an analysis of levels and types of stigma, discrimination, and internal stigma in a given context, as well as evaluation of program impacts on these aspects of stigma and discrimination. In Mexico and in South Africa, the programs have worked hard to determine key indicators for monitoring and evaluating stigma reduction.

4. Ensure that programs complement the work done by others, and help to foster a comprehensive response.

Working collaboratively with others can be crucial for an effective overall response. A program should not work in isolation, so open communication will be vital to any successful endeavor. Networking related to stigma and discrimination has shown itself to be a significant strategy. The Mo Kexteya project in Mexico, for example, has made an effort to get international and national agencies and institutions to recognize the importance of addressing HIV-related stigma and discrimination by sharing the results of its work, documenting challenges, developing material to guide this work, and sharing lessons learned.

No single program can undertake everything that needs to be done. The priorities identified in any given situation can be divided among collaborators and allies so that a comprehensive response is delivered. Moreover, sometimes a sustainable long-term response is possible not by attempting to undertake a particular aspect, but instead by encouraging others to get involved and assisting them in getting started. Advocacy (e.g., encouraging authorities to respond to challenges and to undertake their responsibilities) can be crucial to fostering a collective response.

5. Build on existing programming.

While stigma and discrimination reduction seems to be a new panacea, and many institutions, organizations, and individuals are rushing to create new programs and projects, a strategic response must first integrate stigma reduction policies and initiatives into existing programs. A necessary starting point is a basic situational and response analysis that considers issues such as the following: Who is doing what? What could they be doing related to stigma reduction? What help do they need in terms of technical support, tools, training, or planning?

A stigma reduction plan should consider overall and short-term economic benefits. It should look very carefully at mobilization benefits, including what lasting effects it might have on getting people and institutions involved. The first step is in one’s own work: Stigma reduction begins at home.

THE WAY FORWARD: OBJECTIVES AND STRATEGIES

As noted above, program planners must determine objectives, priorities, and strategies for reducing stigma, discrimination, and internal stigma based on a clear understanding of the context. Table 3 provides an example of how the conceptual framework presented above can be used to outline objectives for change and key strategies for future work. By adapting this framework to specific situations, program planners can develop a comprehensive approach for breaking the cycle of stigma, discrimination, and internal stigma.

TABLE 3. APPLICATION OF THE STIGMA AND DISCRIMINATION FRAMEWORK BY THE MO KEXTEYA PROJECT

STIGMA

Sub-theme	*Results of Analysis*	*Objectives for Change*	*Key Strategies for Future Work*
Pre-existing stigma	▪ Deviation ▪ Inferiority ▪ Gender, race, sex, sexual orientation	1. Enhancing acceptance of people living with HIV and groups vulnerable to HIV	▪ Sensitization of key professionals and community leaders ▪ Enhanced visibility of positive images of populations affected by HIV and of people living with HIV ▪ Public sensitization and focused prevention campaigns
HIV-related stigma	▪ Illness of immorality ▪ Exaggerated danger ▪ Imminent death	2. Improving understanding related to HIV	▪ Information packages developed for specific populations ▪ Training and capacity building of key professionals and community organizations ▪ Model development of better or promising practices
Enacted stigma	▪ Identification ▪ Distancing ▪ Restricting	3. Improving procedures and systems	▪ Political leadership in the community as well as in institutions and organizations ▪ Affirmation of policy, codes of ethics and good codes of conduct ▪ Interventions related to "Positive Prevention"—prevention with people living with HIV (often in care settings) and Greater Involvement of People Living with HIV (GIPA)

DISCRIMINATION

Sub-theme	*Results of Analysis*	*Objectives for Change*	*Key Strategies for Future Work*
Human rights as a conceptual base	▪ Lack of knowledge of rights ▪ Impunity and sanctioning ▪ Limitations in monitoring and reporting	1. Increasing knowledge and capacities related to rights and discrimination	▪ Building capacities related to knowledge of rights, gender, documenting violations and presenting and defending complaints ▪ Strengthening capacities related to advocacy ▪ Documenting examples of laws and policies as promising practice
Laws and policies: Legal and political base for action	▪ Legal base of equality and anti-discrimination ▪ Legal guarantees ▪ Contradictions in levels of legislation or policies	2. Enhancing the monitoring of application of laws and human rights	▪ Developing effective systems of lodging and dealing with complaints ▪ Improving media coverage and responses ▪ Enhancing political leadership at all levels (political and institutional)
Practice: Application of laws and policies	▪ Unequal application ▪ Negligence or omission ▪ Confidentiality and unauthorized testing	3. Improving the enforcement of laws and regulations	▪ Imposing sanctions for non-compliance of laws and regulations ▪ Developing policies and regulations on testing and confidentiality ▪ Advocating for policy change (especially around focused prevention, human rights, compulsory testing and breaches of confidentiality)

INTERNAL STIGMA

Sub-theme	*Results of Analysis*	*Objectives for Change*	*Key Strategies for Future Work*
Internalization of context	▪ Experiences of stigma and discrimination ▪ Acceptance of denigration ▪ Loss of control	1. Enhancing capacity building, social capital, and personal development	▪ Building capacities in areas related to personal and social growth ▪ Increasing self-esteem and a sense of self-worth ▪ Improving individual social capital (involvement in social organizations and groups, sense of influence in social spheres and sense of social integrity or trust in social institutions and authorities)
Self perception	▪ Shame ▪ Guilt ▪ Fear	2. Improving support services for people living with HIV	▪ Ensuring quality of care using a holistic approach ▪ Building persons' capacities for economic independence ▪ Maintaining confidentiality in the workplace, health settings, and various social spheres
Protective action	▪ Avoidance ▪ Isolation ▪ Subterfuge	3. Increasing visibility of people living with HIV as productive members of society	▪ Providing more positive role models ▪ Building leadership skills ▪ Strengthening self-support groups

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POLICY Project
c/o Futures Group
One Thomas Circle, NW, Suite 200
Washington, DC 20005
Tel: (202) 775-9680
Fax: (202) 775-9694
Email: policyinfo@futuresgroup.com
Website: www.policyproject.com

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U.S. Agency for International Development
1300 Pennsylvania Avenue, NW
Washington, DC 20523
Tel: (202) 712-0000
Fax: (202) 216-3524
www.usaid.gov