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# **CORE PACKAGE FINAL REPORT:**

## **Mo Kexteya: Reduction of Stigma and Discrimination Related to HIV/AIDS in Mexico**

**POLICY Project**

**June 2004**



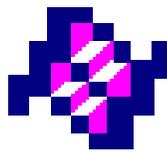
# **Mo Kexteya: Reduction of Stigma and Discrimination Related to HIV/AIDS in Mexico**

**POLICY Project**



**June 2004**

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“Mo Kexteya: Reduction of Stigma and Discrimination Related to HIV/AIDS in Mexico” was implemented by the POLICY Project, in collaboration with the National Institute for Public Health (INSP), the National Center for the Prevention and Control of HIV/AIDS (CENSIDA), Colectivo Sol, the Mexican Network of People Living with HIV/AIDS (Red Mexicana), Letra S, Empresa MEDILEX, and the National Front of People Affected by HIV (FRENPAVIH). Additional support was provided by USAID/Mexico through the MEASURE Evaluation Project and by the Inter-American Development Bank. INSP coordinated the project through its UNAIDS Regional Collaborating Center.



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## Abstract

In August 2002, the first phase of POLICY Project's Core Package on the Reduction of Stigma and Discrimination Related to HIV/AIDS in Mexico (Proyecto Mo Kexteya) was launched in response to a request from the Mexican National Center for the Prevention and Control of HIV/AIDS (CENSIDA) to help develop indicators for a baseline measure of stigma and discrimination in Mexico and to identify innovative approaches to reducing this stigma. Completed in January 2004, the phase—a diagnostic phase—was designed to lay the groundwork for reducing HIV/AIDS-related stigma and discrimination by addressing it in a holistic manner through careful analysis and by developing replicable interventions.

This report examines the four components of the diagnostic phase and outlines the process of developing an action plan to mobilize partners, build a policy dialogue, and undertake interventions to reduce stigma and discrimination. It also highlights some of the main results, which include

- empowering people living with HIV/AIDS (PLHAs) to actively tackle both the internal and external manifestations of stigma and discrimination;
- identifying crucial elements of HIV-related stigma and discrimination in health service delivery;
- identifying necessary changes in public policy and legal reforms to reduce discrimination against people affected by HIV/AIDS, including in the workplace;
- showing how public perception of PLHAs, as influenced by powerful media images, can be improved and, thus, help reduce stigma and discrimination;
- mobilizing key actors in the country to address HIV-related stigma and discrimination; and
- developing an activity plan and mobilizing other agencies and donors to support initiatives for reducing stigma and discrimination related to HIV/AIDS in Mexico.
- reducing HIV-related stigma and discrimination is a crucial part of building an effective and sustainable response to HIV/AIDS—in all aspects, including prevention, care, capacity development, and program management.



## Abbreviations

AIDS	acquired immune deficiency syndrome
CENSIDA	National Center for the Prevention and Control of HIV/AIDS
FRENPAVIH	National Front of People Affected by HIV
HIV	human immunodeficiency virus
INSP	National Institute for Public Health
MSM	men who have sex with men
NGO	nongovernmental organization
PLHA	person living with HIV or AIDS
Red Mexicana	Mexican Network of People Living with HIV/AIDS
UNAIDS	Joint United Nations Program on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS



## Introduction

### What Are Stigma and Discrimination?

In the late 1980s, there was a move to take a more detailed look at the global AIDS epidemic. This look came to a clear conclusion: the majority of those affected by HIV had one thing in common—they were in some form or another marginalized within society. This led persons like Jonathan Mann, then head of the Global Program on AIDS in the World Health Organization, 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 negation.

“Stigma is a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from an adverse social judgment about a person or group” (Weiss et al., 2001). The Joint United Nations Program on HIV/AIDS (UNAIDS) adds its own definition of stigma: “Stigma is a powerful means of social control applied by marginalizing, excluding, and exercising power over individuals who display certain traits” (UNAIDS, 2000a).

Discrimination, as defined by UNAIDS in the *Protocol for the Identification of Discrimination Against People Living with HIV*, refers to “any form of distinction, exclusion, or restriction affecting a person, usually, but not only, by virtue of an inherent personal characteristic, irrespective of whether or not there is any justification for these measures” (UNAIDS, 2000b).

### The Inception of POLICY’s Core Package in Mexico

Since the beginning of the AIDS epidemic in Mexico, HIV cases have been concentrated in gay communities and among men who have sex with men (MSM). HIV-related stigma and discrimination in Mexico has included refusal to treat persons living with HIV, inadequate or inappropriate treatment, refusal to hire or firing without just cause, lack of confidentiality, and avoidance. It has also included violence—sometimes even causing death—against persons living with HIV or persons or suspected of having HIV. Gay men and MSM have long been a target of hatred and disdain; many are forced to lead double lives, hiding their sexual orientation. As a result of not wanting to be publicly identified with AIDS or homosexuality, reaching these men with prevention messages has been hindered. Because bisexuality can be common in these situations, it is critical to contain the epidemic by reaching MSM with prevention messages and tools and empowering them to consistently undertake safer sexual practices. To do this, addressing the underlying causes of stigma, as well as the surface manifestations of discrimination, becomes a crucial aspect of an effective response.

*“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.”*

Eugenio, diagnosed with HIV since 1988

In 1992, the National Commission on Human Rights in Mexico adopted a stance on AIDS. As a result, Mexico adopted a national norm in 1995 that stated medical personnel could not discriminate against a person with HIV or AIDS. In 2000, UNAIDS asked national programs to begin gathering information on areas including stigma and discrimination in their national monitoring. In 2001, the Mexican National Center for the Prevention and Control of HIV/AIDS, CENSIDA, asked the POLICY and MEASURE Evaluation projects, both USAID-funded projects, to help develop tools for monitoring HIV-related stigma and discrimination. By 2002, at the 14<sup>th</sup> International Conference on AIDS in Barcelona, the Minister of Health of Mexico, Dr. Julio Frenk, proposed a “third generation” of epidemiological monitoring—that measured stigma and discrimination—to assess progress in this area.

Such was the setting for POLICY’s decision to respond to CENSIDA’s request and launch a core package of activities in August 2002 to help develop indicators for a baseline measure of stigma and discrimination in Mexico and to identify innovative approaches to reducing this stigma. The package ultimately formed one part of Mexico’s response to the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) accords and to a key strategic objective in the National Five-Year Plan of Action that states that the national program will strive to reduce the stigma around HIV/AIDS.

To achieve an effective and sustainable response to HIV/AIDS, programs and policies dealing with HIV/AIDS prevention, treatment, and care have to address stigma and discrimination. Stigma is an all-encompassing fact of life for people living with HIV/AIDS (PLHAs) in Mexico, and many hope to reduce stigma through positive action. The Mexican government has repeatedly stated its own commitment to reducing stigma and discrimination, and consistently cites it as a top priority. Dr. Julio Frenk noted in a recent speech that there are two epidemics in Mexico—HIV/AIDS and HIV/AIDS-related stigma and discrimination—and we need to deal with both at the same time.

*“It took a lot of effort to learn to live with HIV and keep on with my life.”*

Juan, diagnosed with HIV in 1997

## **Core Package Objectives and Components**

The package’s overall aim is to contribute to the reduction of HIV-related stigma and discrimination in Mexico. The objective of *Phase 1* (August 2002–January 2004) was to gain an increased understanding of stigma and discrimination, how to measure it, how it affects the effectiveness of the response to HIV/AIDS, and what can be done to reduce its prevalence. To achieve a complete understanding, the phase was designed to investigate

the types of stigma surrounding PLHAs, stigma and discrimination in the provision of health services, and the roles of public policy and law and the media in perpetuating or reducing stigma and discrimination.

In reflection of its focus, the project was organized into four components:

1. Internal Stigma among People Living with HIV/AIDS
2. Stigma and Discrimination in Healthcare Settings
3. Public Policy and Advocacy: Identifying legal and normative interventions to reduce stigma and discrimination
4. Media and Images of PLHAs

Apart from its research objectives, the project also aimed to increase the capacity of PLHAs, communities affected by HIV, health professionals, and journalists to recognize and reduce HIV-related stigma and discrimination. Each project component is discussed in greater detail in Section II of this report.

## **Implementing Partners**

The project adopted an overall multisectoral approach, mobilizing and involving many actors. To implement the core package, POLICY collaborated with both public and nongovernmental (NGO) partners, including two PLHA networks. The partners included CENSIDA, the National Institute for Public Health (INSP), Colectivo Sol, Mexican Network of People Living with HIV/AIDS (Red Mexicana), Letra S, and the National Front of People Affected by HIV (FRENPAVIH). The project also drew on the expertise of local consultants. Through separate funding from USAID/Mexico, the MEASURE Evaluation Project worked with INSP to conduct a survey of health service providers in three states, arriving at a baseline measurement of stigma among that target group. The MEASURE activities were designed and implemented as a complement to and an integral part of the POLICY core package.

The POLICY core project sought partners with experience in stigma and discrimination or the potential to create interventions to reduce HIV-related stigma and discrimination. The Red Mexicana has been in the forefront of community research and training on issues related to living with HIV, including training on leadership and the correct use of medication. Colectivo Sol, active since the beginning of the epidemic, has a long track record in HIV prevention among marginalized populations and in organizational capacity development of NGOs. Letra S produces an AIDS supplement in a leading national daily newspaper and has been highly active in the AIDS response, especially in the areas of communication and public discourse. FRENPAVIH, a national PLHA network, has been instrumental in advocating for the rights of persons living with HIV, essentially focusing on access to antiretroviral medication and proper medical treatment. The local consultants brought on board had established track records in law, ethics, human rights, and advocacy related to policy reform. CENSIDA, responsible for the national AIDS program, played a pivotal role in all aspects of the project. Phase 1 was coordinated by INSP through its UNAIDS Regional Collaborating Center.

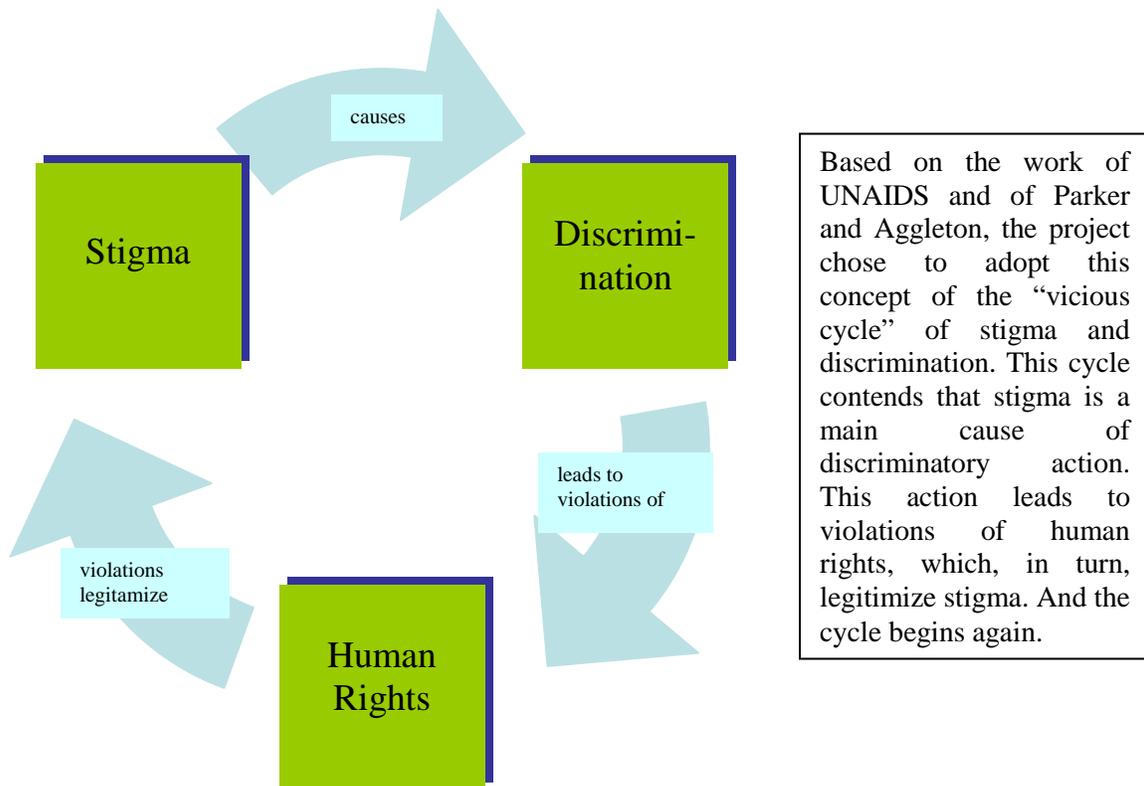


## A Multidimensional Approach to Understanding Stigma and Discrimination

### Identifying Indicators and a Conceptual Framework

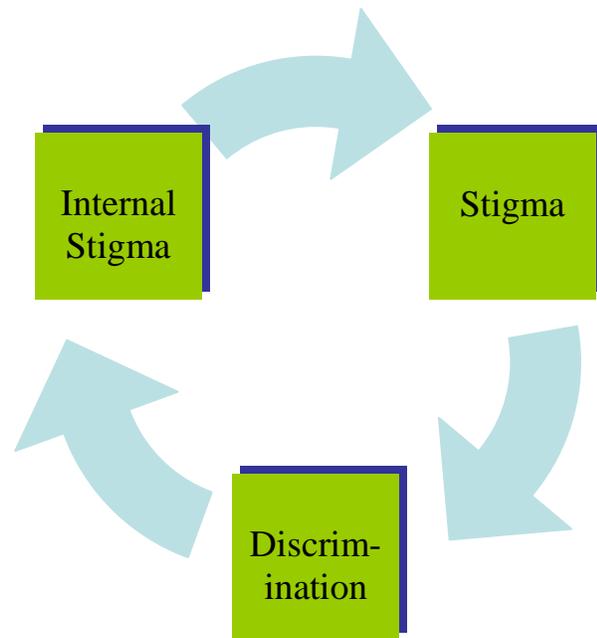
The first step in the core package was to bring together local and international experts working on HIV prevention, care, communications, advocacy, and human rights. A three-day Stigma and Discrimination Experts Group Meeting, co-funded by the Inter-American Development Bank, INSP, and the POLICY Project, was held in Mexico in August 2002 and was attended by all of the implementing partners and CENSIDA. It resulted in the clarification of project goals; a conceptual framework to guide the diagnostic activities (see the following two figures); and a preliminary set of indicators for measuring internal stigma, stigma among healthcare providers, legal and normative protections against stigma and discrimination, and the way that HIV/AIDS and PLHAs are portrayed in the media. The conceptual framework, in its evolved state, is presented in Section III.

#### The Conceptual Framework<sup>1</sup>



<sup>1</sup> For more information on the framework developed by Parker and Aggleton, refer to the following: Parker, Richard, and P. Aggleton. 2002. *HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action*. Prepared for the Horizons Program. New York: Population Council.

To this conceptual guide, the team working on the core package's four components added the critical, and largely unexplored, aspect of internal (or internalized) stigma, especially as it concerns persons living with HIV/AIDS but also including populations key to the epidemic in any situation. This leads to a reworking of the cycle to include linking stigma and discrimination in a cause-effect relationship as well as to internal stigma that, in turn, accepts and, in some cases, reinforces stigma. And again the cycle begins.



## Component Activities and Methodology

The main activities under the four components of the project are summarized below, and a detailed discussion of each component follows.

1. *Identifying and addressing internal stigma among PLHAs.* INSP collaborated with Colectivo Sol and the Red Mexicana on research designed to improve the understanding of internal stigma surrounding HIV/AIDS and how it affects PLHAs' access to and use of essential services. The network took the lead role; INSP provided technical assistance related to project design, methodological issues, quality assurance, and survey instruments and analysis. The research, conducted during 2002–2003, included interviews and focus groups, using PLHA facilitators for all phases.
2. *Measuring stigma and discrimination among healthcare providers.* INSP, under a subcontract to the MEASURE Evaluation Project, conducted qualitative focus groups and quantitative survey research during 2003 to understand the prevalence of HIV/AIDS-related stigma and discrimination in healthcare settings, particularly among doctors, nurses, and receptionists. The survey was conducted in three locations: Mexico City, the state of Yucatan, and the State of Mexico. INSP presented the findings and recommendations to health officials in March 2004. In collaboration with MEASURE, INSP will further refine the survey instrument and apply it to a larger sample population in 2004–2005. The results will provide CENSIDA with a nationally representative set of baseline data.

3. *Identifying legal and normative interventions to reduce stigma and discrimination, with a special focus on the workplace.* INSP worked with local consultants to (a) assess the legal and normative environment related to stigma and discrimination; (b) identify lessons learned about PLHA advocacy activities to date, focusing on stigma and discrimination; (c) assess the institutional capacity of FRENPAVIH and the skills of its individual members; (d) conduct focus groups with labor unions to better understand current initiatives addressing stigma and discrimination around HIV/AIDS and other topics; and (e) suggest policy changes that will reduce stigma and discrimination against PLHAs, with a particular focus on the workplace.
4. *Changing the way HIV/AIDS and PLHAs are represented in the media.* Letra S, a local media NGO, reviewed the coverage of HIV/AIDS and PLHAs in print media during the year 2002. Using the results of the media scan, Letra S designed a sensitization curriculum for journalists and conducted a pilot training in October 2003 with 12 journalists from Mexico City. To provide materials that offer an alternative view of PLHAs, Letra S developed a photojournal, “Frente a la Vida,” that tells the stories of eleven people living with HIV/AIDS. The photojournalist who wrote “Frente a la Vida” is HIV positive.

## **Component 1: Internal Stigma among People Living with HIV/AIDS**

### ***Background***

One of the least understood areas of stigma was internal stigma. Therefore, the project team added it to the adopted conceptual framework, thus illustrating the internalization of the stigma-discrimination process, in persons living with HIV (see Figure 1).

Internal stigma refers to perceived stigma or the internal manifestations of accepted stigma or of negative social perceptions transformed into fear, anxiety, or hurt (sometimes referred to as internalized stigma). Internal stigma can have many forms: deep-seated levels of self-abhorrence or self-denigration or surface level reactions of shame, blame, or guilt.

This component’s principal objective was to increase the understanding of internal stigma in Mexico in order to design effective programs to combat both its causes and its effects. The research team focused on the internal stigma experienced by HIV-positive MSM.

A central characteristic of the component was the empowerment of PLHAs. The Red Mexicana conducted most of the research and its members are PLHAs dedicated to capacity building for PLHAs, to disseminating state-of-the-art information on issues related to living with HIV, and to technical support for PLHAs, with close collaboration with INSP.

## ***Process***

Component 1 encompassed a *qualitative study* using participatory tools developed for community assessments.

A small team of PLHAs was chosen to comprise a community research team, and with assistance from INSP researchers, the team developed a research protocol and study instruments. They tested in-depth interview and focus group guides and organized a workshop and trained the interviewers and focus group facilitators—all of whom were PLHAs.

The facilitators then conducted focus groups for PLHAs in three states (one focus group in each state; a total of 13 PLHA participants, with HIV-positive MSM primarily from urban environments). The focus group notes were transcribed and a collective analysis was undertaken. During the second phase of the research, the team conducted 30 in-depth interviews (10 in each state). The notes were transcribed, set into matrix analysis, and again a collective analysis was undertaken. The team identified key themes and conducted another level of analysis of the data.

Finally, the research team worked on the conclusions and needs for next steps and collective action. They then worked on the concept for and content of workshops for PLHAs dealing with internal stigma and the key elements for workshops with health professionals that touched on internal stigma.

## ***Findings***

The recurring themes from the focus groups and in-depth interviews shed new light on what we mean by internal stigma, and what it means in Mexico to live as an HIV-positive man who has sex with men.

1. Isolation
  - Keeping to oneself was a common reaction, especially just after receiving news of test results. This was most true when there were physical manifestations, such as weight loss and lipodystrophia associated with HIV.
2. Hiding or subterfuge
  - One continually hid different levels of truth—related to HIV status, sexual orientation, drugs, and so forth. Keeping key secrets about your life meant that you were always alone.
3. Morals and morality
  - Shame, guilt, and self-blame were ever present. The role of the church in guilt and shame was a constant question.

*“I felt a lot of rage and anger towards myself; it took a lot to get over it. I felt as though I had betrayed myself, that I had betrayed my son.”*

Niza, diagnosed with HIV in 2000

4. Health and welfare
  - Loss of confidentiality in healthcare and the workplace was common.
  - There were many problems in the steady supplies of treatment.
  - The loss of income or the fear of loss of income was a constant worry.
  - Loss of independence was a major psychological burden.
5. Sexuality and sexual orientation
  - For many, there was a superimposition of homosexuality and AIDS and the elements of stigma and denigration that accompany homophobia in a machismo society.
  - It was difficult to develop or maintain a relationship or to talk about one’s status in a new relationship.
6. Living or dying
  - Many healthcare workers seemed to equate HIV with death.
  - Most thought about suicide as an option during the process of accepting the news of their status.
  - The fear of losing one’s physical capacities was constant.

*“Learning I was HIV positive was a terrible blow. I lost the will to continue.”*

Mauricio, diagnosed with HIV in 1999

7. Solidarity
  - Support groups were of great help.
  - Getting involved in finding common solutions helped on many levels.
8. Social networks
  - Family support (physical, emotional, and spiritual) was vital.
  - There were few cases of rejection within the close family but many cases in the extended family.
9. Planning
  - It was hard to make plans for anything far in the future. This meant that often one simply did not accept invitations or take advantage of many opportunities.
10. Social equations
  - Two common equations often got mixed together: homosexuality = AIDS = death.

## ***Conclusions and Recommended Interventions***

The project found that internal stigma can be illustrated via three key interrelated elements: one's perception of self, one's physical and social environment, and one's protective actions. Recurring aspects of one's perception of self was a negative triumvirate: shame, blame, and guilt. This perception, combined with fear, meant that one experienced life filled with anguish and a sense of self-loathing. Recurring aspects of one's environment were the loss of control manifested in loss of economic independence, physical deterioration, and the loss of any sense of social worth in a world of denigration and prejudice. How one dealt with these aspects—setting limits, avoiding action, and hiding the truth and oneself—actually fed into and nourished all the negative feelings.

The team identified the following interventions to help reduce internal stigma:

1. Building self acceptance through (a) finding and illustrating positive role models, (b) positive thinking or thinking in terms of I can and I will, (c) accepting one's condition and oneself, (d) accepting others, and (e) finding means of opening up to others with the truth.
2. Building individual and organizational capacities through (a) capacity building to support independence, (b) leadership training, (c) capacity building of self-support groups, (d) facilitation and group dynamics training, (e) advocacy skills training, and (f) counseling training.
3. Building better support systems through (a) health services free of stigma and discrimination, (b) guidelines for maintaining confidentiality, (c) referral systems for self-support and other community services in health settings, (d) income generating opportunities, and (e) campaigns encouraging early or regular testing for men who have sex with men and other at-risk populations.
4. Building social capital through (a) increased meaningful involvement, (b) a better sense of influence and sense of social integrity, and (c) the support of social networks.

## ***Recommendations for Follow-up Action***

The following tools and initiatives should be developed to further reduce internal stigma in Mexico:

- models for addressing internal stigma through mechanisms such as self-support groups;
- campaigns and interventions to address stigma and discrimination within the gay communities themselves and the larger community;
- a quantitative baseline study on internal stigma in PLHAs;
- a diagnostic of the role of religion in creating and confronting internal stigma;
- the building of social capital and related skills of PLHAs as trainers, facilitators, and public speakers; and

- the building of skills related to advocacy and documenting discrimination.

Key indicators for measuring internal stigma include the following:

- # of persons who isolate themselves because of HIV
- # of persons who state that they have lied about their HIV status
- # of persons who state that they have hidden their status while seeking employment or in their workplace
- # of persons who state that HIV is a result of their sexual orientation
- # of persons who state that they stopped having sex because of acquiring HIV
- # of persons who state that they have avoided seeking health services because of shame related to their HIV status
- # of persons who state consistent condom use in penetrative sex
- # of persons who state having had suicide tendencies or idealization because of their HIV status
- # of persons who state having felt HIV-related guilt linked to religious precepts

## **Component 2: Stigma and Discrimination in Healthcare Settings**

### ***Background***

For a couple years, CENSIDA, USAID, and its contracting agencies explored how they might investigate stigma and discrimination, especially related to health service delivery. There was also a keen interest, especially by the Mexican Minister of Health, in developing indicators that might serve in epidemiological studies.<sup>2</sup> Over time, the MEASURE Evaluation Project and the POLICY Project came together to design an overall project on HIV-related stigma and discrimination. MEASURE, in close collaboration with CENSIDA, provided financial and technical support to INSP to measure stigma and discrimination in healthcare settings. INSP houses one of Latin America's important UNAIDS collaborating centers. It is a research and teaching institution where people from throughout the region come to complete Masters or Doctoral programs.

The principal objective of Component 2 was to increase knowledge of the barriers to access and use of health services that are influenced by HIV-related stigma and discrimination. There was also an interest in determining priority indicators for measuring stigma and discrimination in the health sector and in developing an instrument that might be used in other settings. The project's ultimate goal was to provide guidance to help inform interventions to reduce stigma and discrimination and their negative effect in the delivery of health services.

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<sup>2</sup> Second Generation Epidemiological Surveys are gathering more and more information on behavior. Third Generation Surveys are interested in adding indicators related to stigma.

## ***Process***

Component 2 was undertaken in two distinct phases: a qualitative study and a quantitative survey.

The *qualitative study* (months/year) included a literature review and a review of existing indicators related to stigma. The INSP research team then developed interview guides for various concerned populations, including diverse health sector professionals, PLHAs, MSM, and sex workers. They undertook 36 in-depth interviews in three Mexican cities (Puebla, Cuernavaca, and Mexico City) with health service professionals<sup>3</sup> (14), MSM PLHAs (5), HIV-positive women (4), sex workers (7), and heterosexual men living with HIV (3) and small groups of PLHAs (3). The research team often identified and contacted persons through snowballing techniques and visited diverse healthcare settings to observe practices and procedures. The team then analyzed the interviews and observations. Information on health service access and use by injecting drug users from other studies was also taken into consideration in the analysis.

The findings from the qualitative study served as fodder for a *quantitative survey* questionnaire drafted by the INSP research team, in collaboration with representatives from CENSIDA and MEASURE. INSP identified and trained a survey team and then piloted and finalized the instrument. The team gave the survey in the State of Yucatan, Mexico State, and Mexico City, to 373 health professionals working in hospitals, health centers, and health clinics. The sample of professionals came from three health systems: IMSS, the social security system for persons in formal employment; ISSTE, the social security system for government employees; and SSA, the health ministry system for persons who do not qualify for the other systems, are unemployed, or are working in the informal sector. The team surveyed five different wards in the hospitals. A total of 131 men and 239 women were surveyed. Of these, 65 percent had completed at least one degree; 45 percent were doctors; and 40 percent were nurses.

## ***Findings***

*Pre-existing stigma was illustrated in negative reactions to homosexuality, promiscuity, and, in some cases, poverty.* Approximately a quarter of the 373 health professionals surveyed thought that homosexuality was the cause of AIDS in Mexico. More than 25 percent said they would not share a house with a homosexual, compared to only 13 percent that said they would not share a house with a PLHA. Approximately 75 percent thought that PLHAs were to blame for their condition.

*Stigma related to HIV came in different forms: a poor knowledge of HIV, an exaggerated sense of risk, and the close association with death.* The level of knowledge of the persons surveyed was generally high. However, the findings in some areas were striking in the low level of understanding illustrated. For example, 25 percent of those surveyed agreed with the statement that being “HIV positive was the same as having AIDS”; 14 percent (and another 3% who did not know) did not think that a mother could transmit HIV to her

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<sup>3</sup> The healthcare providers interviewed included doctors, dentists, nurses, laboratory workers, among others.

child via breast milk; 8 percent did not know that an asymptomatic HIV-positive person could transmit HIV.

*Enacted stigma was illustrated in three main areas: identification of infected persons, isolation from others, and the imposing of restrictions.* Although 87 percent said that testing should be voluntary, many thought it should be compulsory for particular populations: 86 percent thought sex workers should be tested, 66 percent for MSM, and 55 percent for all foreigners. Although 90 percent said that HIV status should be confidential, approximately 40 percent said that employers had the right to know the status of their employees. It was noted that various hospitals had procedures to visually mark HIV-positive patients through signs and colored coded wristbands.

Many health professionals thought that it was best to isolate HIV patients to protect the patient from infections from other patients (74%); to protect other patients from them (46%); and to protect medical staff (30%). Although 75 percent agreed that universal precautions were sufficient for PLHAs, approximately 50 percent said they would use additional precautions if they suspected or knew someone to be HIV-positive. Note that 15 percent of those surveyed said they could visually identify a person with HIV.

Almost one fifth of those surveyed thought that a PLHA should be prohibited from using public services, such as swimming pools or public washrooms. Thirty-six percent said HIV-positive surgeons should not be performing surgery. Sixty percent said HIV-positive women should be prohibited from having babies. Almost 25 percent would not buy food from an HIV-positive person, and 43 percent would not consult a dentist with HIV.

*The differences in responses by state and type of institution, while they existed, were not significant.* There were differences by gender and level of education, but women were generally less educated than men. Where differences were clear was between respondents who had undergone some form of training related to HIV (including participation in an AIDS conference) versus those who had no training. Twenty-three percent of those with some AIDS training thought that AIDS and HIV were the same thing versus almost 40 percent for those without training. Of those with training, 14 percent thought that PLHAs should be prohibited from using public services (pools or washrooms), compared to 26 percent of those without training.

*“The psychologist gave me the news suddenly, ‘You don’t have much time,’ he said and recommended that I get my life organized, bring some order to it... I took it very hard, very strong, like a death sentence even though there was no evidence of disease. I quit school thinking, why continue studying?”*

Raymundo, diagnosed with HIV in 1988

### ***Conclusions and Recommended Interventions***

Although those surveyed were found to have a reasonable level of understanding related to HIV and transmission, the survey identified definite deficiencies in knowledge related to mother-to-child transmission, the stages of HIV infection, the results of good treatment, the effectiveness of universal precautions, and some aspects of transmission.

Considering that these health professionals are not only sources of primary services but also sources of important information, their level of understanding in these areas should be raised.

The survey identified negative attitudes that are clear indicators of stigma; many are related to pre-existing stigma, such as homophobia and attitudes about sexuality. There was a definite distinction among the perspectives of those surveyed regarding who were innocent persons and who were guilty persons amongst the infected; consequent discriminatory or stigmatizing practices were not uncommon.

The survey revealed a high level of self-perceived risk among healthcare professionals, as well as many levels of enacted stigma related to the identification of persons with HIV, ranging from the need to test subpopulations to the need to isolate them to protect other patients or health professionals.

*“Where I did feel discrimination ... was in the AIDS Center because they did not want to give any medication to either me or my partner. That was in 1997. They argued that they had to give families the preference, meaning heterosexual men, women, and children. They didn’t want to give us any because we were homosexuals. My partner questioned their decision, “But aren’t we a family? We are a couple and have lived together for 14 years.”*

Raymundo, diagnosed with HIV in 1988

Some of the areas for interventions, further exploration, and research included:

- further analysis of the database and reworking the study instrument based on this analysis;
- exploration of the attitudes toward sexuality, homophobia, transgender persons, and drug users;
- further exploration of knowledge, perceptions, and practices among social workers, psychologists, counselors, and health professionals working in outpatient wards; and
- exploration of the effects of various training and personal experience and the identification of options and needs for training in particular wards and particular professions.

Crucial process issues noted included:

- involvement of PLHAs in the sensitization and training of health professionals,
- affirmation of universal precautions, and
- affirmation and knowledge of codes of conduct and ethical codes for health professionals.

### ***Recommendations for Follow-up Action***

Key follow-up actions include the following:

- undertaking a multivariate analysis of the database from the baseline survey;
- reworking the instrument and selecting indicators for use in general health and population surveys;
- undertaking further survey work to increase the size of the sample;
- designing training course curriculum and material for health professionals;
- conducting a qualitative follow-up study to look at sexuality, homosexuality, and drug use issues;
- affirming universal precautions and professional codes of conduct; and
- involving PLHAs, affected populations, and unions in designing and implementing interventions with health professionals.

Suggested key indicators include perceptions and knowledge related to

- the right for positive women to decide to have a child
- differentiation of living with HIV and having AIDS
- right to confidentiality and compulsory testing
- innocent and guilty infections
- causes of infection
- association with imminent death
- prevention knowledge
- treatment knowledge

### **Component 3: Public Policy and Advocacy: Identifying legal and normative interventions to reduce stigma and discrimination**

#### ***Background***

Over the past two decades, initiatives to address the AIDS epidemic have increasingly included an examination of law, ethics, and human rights. However, while much work has been done on human rights and AIDS, it has not always been connected to a general analysis of stigma and discrimination and a focus on measurement.

To date, AIDS-related advocacy in Mexico has focused largely on access to antiretroviral therapy; it is time to broaden this focus to include issues of rights to integral health services free of discrimination. There are legal guarantees for access and a slow but sure expansion of making that guarantee a reality.

#### ***Process***

Component 3 included assessments of (1) public policy, (2) unions' policies and practices, and (3) the advocacy capacity of PLHAs and HIV-related organizations.

*Public policy.* Empresa MEDILEX, a law office dedicated to law, policy, and medicine conducted an assessment—related to HIV/AIDS or populations more affected by HIV—at the national level, in three states, and, where pertinent, at the municipal level (in the three states). The assessment included an *analysis of judicial law and policy* ranging from the Constitution and federal anti-discrimination law to the health, civil, penal, labor, social security, and public security laws. It also analyzed the application of the laws. The principal objectives were to identify the legal and policy reforms needed to address stigma and discrimination, the legal basis for confronting HIV-related stigma and discrimination, and the state of public policy and policy application.

*Unions.* A consultant, with a distinguished history in health and human rights, assessed four unions’ policies and practices related to HIV/AIDS, stigma mitigation, and, whenever possible, HIV-related stigma and discrimination. The union assessment included interviews with key informants, and the principal objectives were to increase knowledge of union policy and practices related to AIDS, stigma, and discrimination in order to identify possible avenues, existing materials, and allies that could be useful for union-related interventions.

*Advocacy.* INSP, a consultant with Letra S, and FRENPAVIH assessed the advocacy capacities and needs of PLHAs and the organizational capacity of FRENPAVIH, which has been instrumental in HIV-related advocacy. They also analyzed lessons learned based on three case studies of focused advocacy in Mexico. The assessment was based primarily on interviews, and the analyses were discussed in a meeting held with PLHAs from around Mexico. The assessment’s principal objective was to identify how the national network can best champion the reduction of stigma and discrimination.

## **Findings**

The significant findings of this component included the following:

*There is a solid legal base related to discrimination.* Based on equality, anti-discrimination, and human rights language in the Constitution; the federal law on discrimination; and the international treaties signed by Mexico, there is a general foundation of support for the reduction of stigma and discrimination. There is, however, a lack of systematic practice and most authorities are passive in their addressing of discriminatory acts. There are also insufficient regulations regarding the use of compulsory testing or firing based on test results. In some cases, there are laws that “legalize” discrimination (contrary to the constitution or international treaties), such as the dispositions regarding testing for HIV in the national armed forces law.

*To address policy related to stigma and discrimination, monitoring systems should be improved.* There is a need to reinforce the national Commission on Human Rights in areas related to HIV-related discrimination. Social Security systems have many unequal or discriminatory practices.

*Advocacy for means and mechanisms for reducing HIV-related stigma and discrimination should be reinforced.* There is a need to broaden HIV-related advocacy beyond securing access to antiretroviral treatment. Advocacy can have not only social and political results but also personal results in building self-esteem and social capital. A

good example of a law that should be promoted includes the penal code for the city of Mexico. To be effective, advocacy programs should be designed based on solid analyses and data. Collective action has the strongest impact but requires capacities for negotiation and patience.

*Individual and organizational capacity development will be crucial in reducing stigma and discrimination.* There is a need to improve capacities for documenting violations of human rights. While working with PLHAs and affected populations, it is important to strengthen their advocacy skills in reducing internal stigma and stigma related to sexual diversity and gender; build their skills in public speaking, working with media, and so forth; and increase their knowledge of HIV transmission and human rights. The organizational capacities of PLHA organizations and NGOs related to planning, administration, documentation, and communication should also be strengthened.

*Public campaigns should include a focus on understanding the key aspects of HIV, accepting PLHAs and communities affected by HIV/AIDS, and understanding the role of stigma in the epidemic.* There is an urgent need to help people understand the difference between HIV and AIDS and to see PLHAs as productive members of society.

*Private enterprises and unions have a role to play in the reduction of HIV-related stigma and discrimination.* Unions have little experience in dealing with HIV-related stigma and discrimination but have some experience in AIDS and in stigma related to other areas such as gender and disability. Workplace policies should be reviewed or created, especially related to consensual testing and confidentiality.

*“Another thing is the ignorance about our rights. Often we are treated as if people are doing us a favor by giving us service. When this happens, the other person—the one supplying the service, be it a doctor, nurse or whatever—feels their power and takes advantage of the situation.”*

Eugenio, diagnosed in 1992

### ***Conclusions and Recommended Interventions***

- There are only a few laws that need to be challenged and revised, but the processes will take time.
- Noncompliance of laws and regulations should result in sanctions.
- Labor laws should include clear regulations related to consensual testing and mechanisms to enforce them must be created.
- Securing rights for same sex couples will set a good example for social tolerance.
- There is a need to promote laws, such as the Mexico City penal code, as an example of good practice.
- Public campaigns must help to differentiate HIV from AIDS, illustrate that testing is not the answer, and show PLHAs as productive members of society.
- Capacity building in the documenting of violations of human rights, advocacy efforts, and the handling of complaint cases is needed for PLHAs and affected populations.
- Legal and other (telephone) support systems should be strengthened.

- This is a good time to work with the healthcare workers union and teachers union to devise policies and education programs related to HIV, stigma, and discrimination.
- Advocacy related to health and stigma and discrimination needs to be strengthened.

## **Component 4: Media and Images of PLHAs**

### ***Background***

Since 1996, Letra S, dedicated to disseminating information on HIV/AIDS, has been editing a regular monthly supplement in a principal daily newspaper, La Jornada, in Mexico City. Armed with this experience, Letra S investigated HIV-related stigma and discrimination portrayed in the print media in three states in Mexico (Yucatan, Mexico State, and Mexico City). The principal objectives were to analyze the image of PLHAs in print media and design intervention strategies to reduce stigma and promote a nondiscriminatory environment that respects the human rights of PLHAs and MSM in Mexico.

### ***Process***

The main activities of Component 4 included (1) monitoring the print media over one year, (2) designing a photojournal of PLHAs, and (3) designing and testing a training workshop for journalists.

*Monitoring.* The component activities began with a literature review in 2002, concentrating on the aspects of AIDS, stigma, and discrimination in the media. Examples of media monitoring were found but none that specifically looked at the issue of stigma. With the assistance of a group of experts, Letra S designed a media-monitoring project that followed 12 daily newspapers in the three selected states over one year. The newspapers were chosen to represent a wide spectrum of dailies and included three from each state and three with a national circulation. The team examined all articles (and photos) that addressed HIV, AIDS, PLHAs, and homosexuality (and synonyms) for a 12-month period, and the information was captured in a specially designed database.

*Photojournal.* A testimonial photojournal covering the lives of PLHAs was designed to raise awareness and sensitize journalists. Ten PLHAs actively participated in the process and their lives were captured in a photojournal of high-quality images and text. They completed a preliminary questionnaire; allowed the photojournalist, himself a PLHA, to take pictures of their everyday life; and participated in in-depth interviews with the project team. The draft photojournal was used and evaluated during the October 2003 journalist workshop (discussed below) and became a final product in December 2003.

*“My fear [talking about appearing in the media] is not for me, but for the possible consequences for my friends and family. What holds me back is the negative reaction or discrimination they might suffer as a result.”*

Juan, diagnosed with HIV in 1997

*Training and sensitization.* The design and testing of a training and sensitization workshop for selected journalists was completed with the assistance of POLICY Project consultants. Letra S and the consultants developed a four-day workshop and invited journalists from the newspapers selected for the monitoring review. The workshop was conducted in collaboration with INSP and CENSIDA. Nine specialists and three PLHAs covered thematic areas including epidemiology, human rights, and the role of the media. The 12 participating journalists completed pre- and post-workshop questionnaires. Following the workshop, participants published 18 follow-up articles in seven out of the eight participating newspapers.

## ***Findings and Results***

### *Newspaper monitoring*

A total of 907 articles and 298 images were analyzed from 12 newspapers over one year; 535 (59%) had HIV/AIDS as the central theme, 121 (13%) were about PLHAs, and 251 (28%) were centered on MSM. The Yucatan papers had a higher percentage of coverage of HIV/AIDS; the national papers had a higher percentage of coverage of PLHAs; and the papers identified as “tabloid” had a higher percentage of coverage of MSM.

Some of the main findings included the following:

- Stigma related to homosexuality seemed more prominent than that related to HIV. One quarter of articles and photos concerning MSM were defined as negative or stereotypical. A quarter of the images associated homosexuality with a crime or misdeed. This was especially true in alarmist papers.
- Although still significant, the levels of stigma were not as high as expected: 13 percent associated AIDS with death; 7 percent associated AIDS with homosexuality; and 10 percent of articles used stigmatizing terms or expressions in reference to HIV/AIDS.
- Stigma was more evident in images and photos than in text. A third of the images of PLHAs associated them with death and a third had the faces of PLHAs veiled or covered, which often allows for an association with shame, guilt, or fear.
- There was a surprisingly low representation of the views of PLHAs in the coverage. Although 20 percent of the articles were centered on PLHAs, only a small number actually used these persons as the source of information in the article.
- NGOs were the third most important source of information after doctors and health officials. A third of the images related to AIDS included images of activists and NGO representatives.
- Although only 6 percent of all newspaper articles reported on discrimination, complaints that centered on PLHAs were the focus of a third of the articles. Institutions in the health sector were most often cited in reported complaints of discrimination.

### *Photojournal*

Some of the main results included the following:

- Overall, 12 PLHAs participated in the process.
- Ten PLHAs allowed their stories to be told; eight men and two women (three were heterosexual and seven were gay or MSM). Three of these persons kept their status confidential.
- Of 310 photos taken, 68 were included in the final publication.
- The evaluation of the photojournal in the journalist workshop noted that the journal was well done; the stories were designed to strengthen sentiments of solidarity and support; and the messages were uplifting. The journalists noted the difference between those who did not show their faces and those who did; the former associated more with sadness and isolation and the latter with optimism and solidarity.

### *Journalist Workshop*

Some significant results included the following:

- Twelve of 18 invited journalists participated in the four-day workshop.
- The examination of pre- and post-workshop evaluations, which centered on written articles, showed improvements in the handling of information and half showed significant improvements.
- The participants' evaluation of the workshop classified the overall workshop as very good; the expectations met as excellent; and the information on stigma and discrimination as very relevant.
- Participants noted that they gained a broader understanding of HIV and AIDS.
- As a direct result of the workshop, 18 articles were produced in eight newspapers.

### ***Conclusions and Recommended Interventions***

- There are periods of the year when national and international events (such as World AIDS Day or the World AIDS Conference) attract a lot of interest and press coverage. These events or time periods present good opportunities for advocacy and change, and good preparation will help advance the AIDS movement.
- The level of stigma, especially regarding the association between death and AIDS, has no doubt been influenced by the arrival and availability of antiretroviral therapies; it is worth investigating this relationship.
- The public campaigns based on “everyone is at risk” and focusing on women and children have no doubt had a similar influence on the association of AIDS and homosexuality. This too bears investigation.
- The primary sources of information for journalists appear to be governmental institutions, NGOs, and international organizations. These sources should be trained to improve their ability to work with the media. It was noted that “NGOs have educated the media.” This education process should be strengthened.

- Improving the presence of PLHAs in the media would help to sensitize the public and reduce irrational fears of contagion and danger. The effects of images of PLHAs with their faces hidden should be researched.
- The awareness raising and sensitization of journalists can have long-term effects. These processes should involve PLHAs and include a focus on the media's role in reinforcing stigma.

The main intervention strategies include

- in-depth interviews with journalists to better understand needs, attitudes, and motivations in order to develop practical tools to reduce stigmatizing language and images in the media;
- training and sensitization workshops with journalists;
- skills building for gay activists, NGO leaders, and PLHAs to help them work more effectively with the media;
- publication and dissemination of the photojournal; and
- selected media monitoring to survey changes during the implementation of interventions.

Besides the indicators used in the project, new indicators, such as the following, should be included in further endeavors:

1. Sociodemographic information on PLHAs in the media (gender, age, sexual orientation, and so forth)
2. Poverty and class indicators
3. Role and portrayal of the PLHAs in the media (activist, defenders of their rights, passive, victims, and so forth)
4. Relationship of homosexuality with crime, misdeed, or prostitution
5. Articles or images that report stories of gay couples

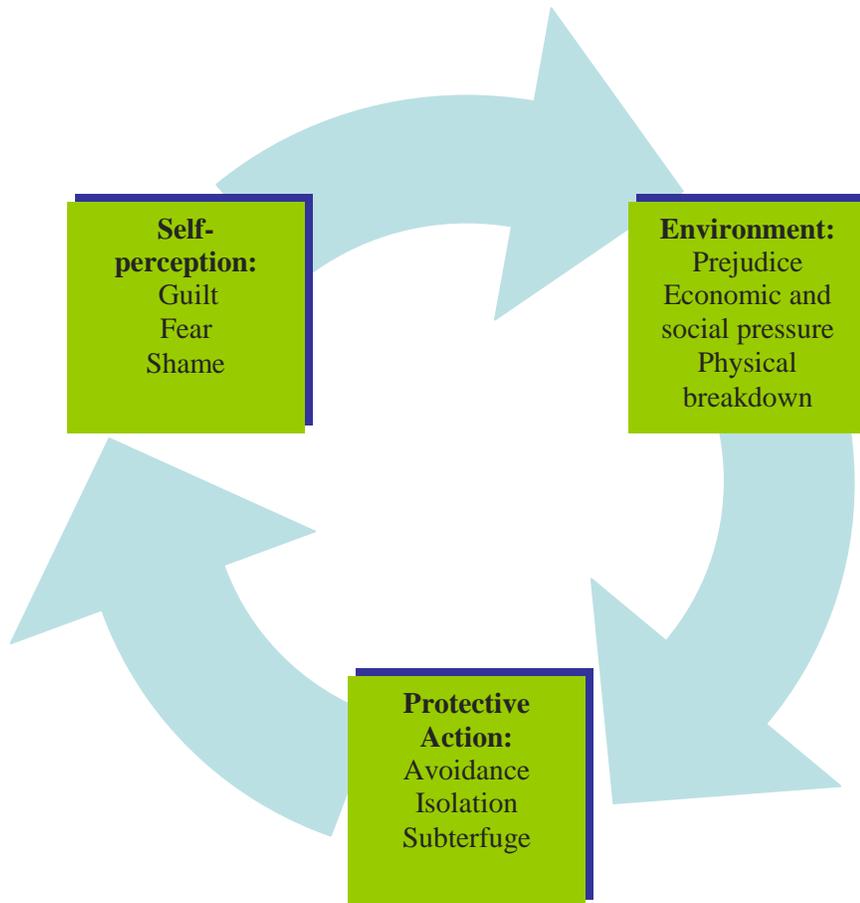


### What do we know now and what should we do?

#### Internal Stigma

##### *Findings*

The key findings related to internal stigma can be categorized in three areas: self-perception, the environment, and protective action. In the area of self-perception, the exploratory phase of the project found three recurring elements: shame, fear, and guilt. To this, one might add anguish. In the area of the environment, the project noted several interacting elements that led to an overall sense of loss of control. These elements included misinformation, denigration, and negative prejudices; economic and social pressures; and physical deterioration. The areas of protective action that were most recurring included avoidance (including denial), isolation, and subterfuge. These three categories interact in a cycle of internal stigma (see below)—each feeding or building on the effects of the other.



### ***Objectives and Strategies for Change***

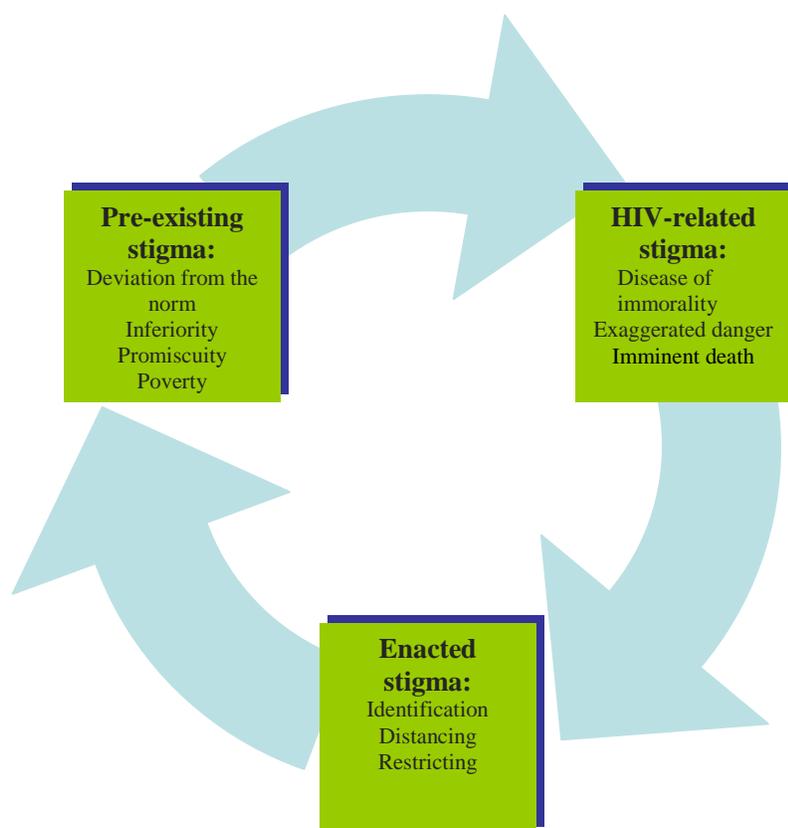
The priority objectives and their corresponding strategies for reducing internal stigma include:

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)
2. Improving support services for persons living with HIV
  - Ensuring quality of care in an optic of holistic health
  - Building individuals' capacities for economic independence
  - Maintaining confidentiality in the workplace, health settings, and various social spheres
3. Increasing visibility of persons living with HIV as productive members of society
  - Providing more positive role models
  - Building leadership skills
  - Strengthening self-support groups

### **Stigma**

#### ***Findings***

Stigma came primarily in three forms: pre-existing stigma, HIV-related stigma, and enacted or tangible stigma (see the following figure). The recurring characteristics of pre-existing stigma included deviation from the norm, inferiority, promiscuity, and poverty. The recurring aspects of HIV-related stigma included immorality, death, and danger. This latter aspect was often related to misinformation and a heightened sense of perceived risk. The pattern of enacted stigma comprised three stages: identify those infected, create a distance from them (often by isolating them), and restrict them (either in prohibited actions or by confinement).



### *Objectives and Strategies for Change*

The three principal objectives and their corresponding strategies to reduce stigma include:

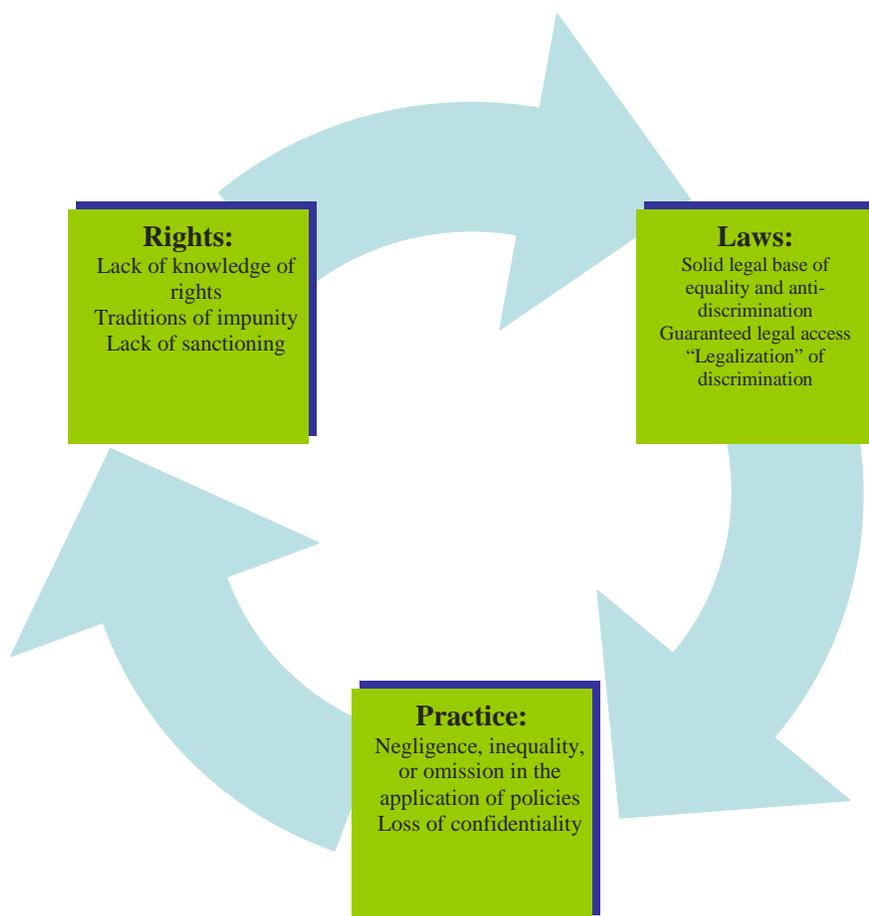
1. Enhancing acceptance of persons living with HIV and groups more affected by HIV
  - Sensitizing key professionals and community leaders
  - Enhancing the visibility of positive images of populations affected by HIV and of PLHAs
  - Implementing public sensitization campaigns
2. Improving understanding related to HIV
  - Developing information packages for specific populations
  - Training and capacity building for key professionals and community organizations
  - Developing model “Better or Promising Practices”
3. Improving procedures and systems
  - Strengthening political leadership in the community and organizations
  - Affirming policy, codes of ethics, and good codes of conduct

- Creating interventions related to “Positive Prevention”—involving PLHAs in prevention activities aimed at others (often in care settings) and GIPA

## Discrimination

### Findings

The exploratory phase of the project examined discrimination related to three broad categories: existing law, the application of law (or practice), and human rights (see the below figure). In the existing laws in Mexico, we found a level of support for equality and anti-discrimination within the Constitution and the international treaties that Mexico had signed. There were, moreover, many cases of guaranteed access to services and to rights and means of redress. However, there was some “legalized” discrimination in a few laws that were contrary to the Constitution or international treaties. The application of the laws was another story. Negligence, inequality, and omission were common in the application of policies and regulations. The loss of confidentiality was also common. In regard to human rights, the project noted a lack of knowledge about what the rights were, which were applicable, and what recourses one had when rights were violated. This was compounded by a history of impunity and major problems in applying laws or resolving areas of redress.



### ***Objectives and Strategies for Change***

Three priority objectives and their corresponding strategies for improving the law and policy environment include:

1. Increasing knowledge and capacities related to rights and discrimination
  - Building capacities related to knowledge of rights, documenting violations, and presenting and defending complaints
  - Building capacities related to advocacy
  - Documenting examples of laws and policies as “Promising Practices”
2. Enhancing the monitoring of the application of laws and human rights
  - Improving effective systems of lodging and dealing with complaints
  - Improving media responses
  - Enhancing political leadership at all levels (political and institutional)
3. Improving the enforcement of laws and regulations
  - Imposing sanctions for noncompliance of laws and regulations
  - Developing policies and regulations on testing and confidentiality
  - Advocating for change (especially around compulsory testing and breaches of confidentiality)

*“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, diagnosed with HIV in 1986



## Conclusions

### Significant Results of Diagnostic Phase

The following are crucial results of the diagnostic phase of “Mo Kexteya: Reduction of Stigma and Discrimination related to HIV/AIDS in Mexico.”

*An increased understanding of HIV-related stigma and discrimination in Mexico.* As outlined in the preceding section, the diagnostic phase gave us a much clearer understanding of HIV-related stigma and discrimination in some vital areas of concern. This understanding allowed us to identify key objectives that would simultaneously work on both root causes of stigma and consequences of discrimination.

*An increased awareness.* The diagnostic phase brought us into contact with many persons working in HIV-related areas, persons living with HIV, and persons affected by HIV/AIDS. The project clearly sought to and accomplished a raised awareness of the role of stigma and discrimination in the epidemic and the importance of understanding and developing interventions for its reduction.

*An increased mobilization of lead actors.* Four distinct teams were involved in the diagnostic phase. The project’s overall coordination team was made up of 18 persons and approximately 75 persons were mobilized—not including the many persons interviewed or surveyed. People came from various backgrounds and included many leading experts in their respective fields. Over 40 PLHAs were involved.

*Improved capacities in participants.* PLHAs and those in affected communities were involved in the project from its inception until completion. They improved their knowledge of stigma and their skills in research methods and communication. Academic and health professionals improved their understanding of the plight of PLHAs and affected populations and learned participatory methodologies.

*Increased mobilization of institutional partners and funds.* One of the unexpected results of the project was the mobilization of partnerships to help develop, implement, and fund interventions aimed at reducing HIV-related stigma and discrimination in Mexico. To date, for example, three institutions have come forward with intentions to fund stigma reduction projects.

*The identification of some key indicators for measuring HIV-related stigma and discrimination.* The development of an indicator list is continuing into the implementation phase and a report is forthcoming.

*The development of an action plan.* A detailed action plan has been created for the intervention phase. This phase will comprise pilot projects, including a distance-learning course on stigma and discrimination for healthcare providers, which will count toward their in-service training annual requirements; capacity building of PLHA networks to reduce internal stigma through peer support groups; dialogue with faith-based

organizations to explore their role in both promoting and reducing HIV-related stigma and discrimination; an awareness campaign to reduce HIV-related internal stigma in the gay community; journalist training on stigma and discrimination; and collaboration with the Ford Foundation to address legal and regulatory changes. Additionally, POLICY is supporting a survey of the top 25 U.S. businesses in Mexico to gather a baseline on their HIV/AIDS-related practices in the workplace. The survey will be used in part to identify companies that are interested in further collaboration to reduce stigma in the workplace.

*“I am like any other person, being seropositive does not stop or limit me, but, on the contrary, it motivates me.”*

Juan, diagnosed with HIV in 1997



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