HIV interventions cannot be fully effective in a stigmatizing or discriminatory environment. Yet, while most national HIV policies call for reducing stigma and discrimination, few programs have been able to operationalize effective stigma reduction strategies. Program planners have run into several obstacles: stigma and discrimination, as concepts, are not well understood; concrete data for justifying investment in stigma reduction have been limited; and prejudices and taboos are difficult to overcome.

**WHAT IS STIGMA?**

Stigma is defined as “an undesirable or discrediting attribute that an individual possesses, thus reducing that individual’s status in the eyes of society” (Goffman, 1963). HIV stigma comes in many forms, including gossip and verbal abuse, judgments, and morally-driven values about people living with HIV and populations that are more vulnerable to infection. It can be manifested in discrimination, including violence and physical abuse as well as loss of jobs and lack of services.
HIV and Stigma

People living with HIV (PLHIV) and most-at-risk populations (MARPs) face various forms of stigma and discrimination. These include rejection by family and friends; physical abuse and gender-based violence; poor treatment by service providers; and the loss of employment, housing, and educational opportunities.

Stigma is also a significant barrier to learning one’s HIV status. Worldwide, an estimated 9 out of 10 HIV-positive people do not know their status. Knowing one’s HIV status is the first step in accessing treatment and care and preparing for the future, including planning for the care of one’s children. By discouraging people from seeking HIV prevention information, testing, and treatment, stigma and discrimination increase vulnerability to infection; the probability of engaging in high-risk behaviors that transmit the virus; and vulnerability to poor health outcomes as a result of delayed or inadequate treatment or inability to adhere to treatment.

Key drivers of stigma can either positively or negatively influence stigma. For example, institutional and cultural facilitators, such as strong enforcement of anti-discrimination laws, can reduce stigmatizing and discriminatory practices. Conversely, individual- and community-level constraints, such as lack of awareness of stigma or its harmful consequences and fear of HIV infection, can increase stigma.

Health Policy Approach to Stigma Reduction

The USAID | Health Policy Initiative, Task Order 1, carried out multiple activities to address stigma by building a solid base of knowledge and evidence on critical issues and then empowering the most affected groups. When commitments of key stakeholders are strengthened, HIV policies and programs have the greatest chance of achieving success and meeting the needs of those most in need.

IMPROVING UNDERSTANDING OF STIGMA AND DISCRIMINATION

One of the project’s key contributions to the HIV field is its work to conceptualize stigma and discrimination: What do these concepts mean? How do they affect people and programs? How can they be measured? The Health Policy Initiative worked with partners to develop indicators to measure various aspects of stigma and discrimination. These tools provide needed data for planning and evaluating stigma-reduction efforts. The project also collaborated with the International Center for Research on Women, Global Network of People Living with HIV/AIDS, International Planned Parenthood Federation, UNAIDS, and academic institutions to design a stigma framework that depicts the key actionable factors that facilitate and drive HIV stigma; the marking of individuals or groups as socially unacceptable based on behaviors, characteristics, and/or HIV status; stigma domains; outcomes (e.g., risk behaviors and uptake of HIV prevention, care, and treatment services); and impact (quality of life and HIV incidence and prevalence). This framework is based on the assumption that all individuals can anticipate, internalize, experience, and/or perpetuate stigma and discrimination.

In addition, the project worked to assess and reduce the internalized stigma felt by PLHIV and MARPs. Internalized stigma can lead to self-isolation and delays in seeking HIV testing and treatment. The project also addressed the intersection of HIV, stigma, and gender-based violence and how these issues affect programs and health outcomes.

EMPOWERING PEOPLE LIVING WITH HIV AND OTHER MOST-AT-RISK POPULATIONS

The Health Policy Initiative has extensive experience building the “social capital” of HIV-positive people and MARPs. Strengthening social capital requires increasing meaningful involvement of PLHIV and MARPs. This requires greater investment in PLHIV networks (e.g., skills, programs, institutional capacity, resources) and, in turn, enables more effective contributions of PLHIV to policy dialogue. Ultimately, PLHIV and MARPs are empowered to influence the social and policy environments that affect their lives and health.

The project strengthened social capital of PLHIV by fostering network formation, building skills (e.g., advocacy, stigma reduction), and facilitating involvement of PLHIV as partners in project activities. For example, the project helped establish and strengthen PLHIV networks in high HIV-affected provinces in China; in countries in the Middle East and North Africa where HIV prevalence...
is low but stigma is pervasive; and with HIV-positive women in Mexico and Vietnam. The project also built the capacity of a multitude of PLHIV groups—such as the Tanzania Network of Religious Leaders Living with or Affected by HIV/AIDS (TANERELA) and the Kenya Network of HIV-positive Teachers (KENEPOTE)—that work on issues ranging from safe disclosure to compassionate care to equality in the workplace.

MOBILIZING DIVERSE SECTORS AND LEADERS TO BREAK THE SILENCE SURROUNDING HIV

The Health Policy Initiative encouraged influential opinion leaders to speak out against stigma and discrimination. For example, the project strengthened the HIV-related capacity of numerous faith-based organizations, including the Muslim and Christian Religious Leaders Alliance for AIDS Control in Mali, the National Baptist Church of South Africa, and two prominent Islamic organizations in Indonesia. The project assisted businesses in Jamaica, Mexico, Mozambique, and other countries to adopt HIV and anti-discrimination workplace policies. The project also trained journalists in China and Tanzania to raise awareness of HIV and promote non-stigmatizing portrayals of those affected by the epidemic. In Latin America, the project worked with academic institutions to integrate stigma sensitization into curricula for health professionals. By addressing the intersection of stigma, discrimination, and gender, the project empowered Kenyan women to work in partnership with community elders to protect the property and inheritance rights of widows and orphans.

FORMULATING AND PUTTING LAWS, POLICIES, AND GUIDELINES INTO PRACTICE

Much of the project’s work with policymakers and civil society advocates has been geared toward designing policies and programs to foster equitable access to services and to prohibit discrimination. In Vietnam, the project facilitated the participation of PLHIV in reviewing and providing recommendations for a draft HIV law. The law, which went into effect in January 2007, ensures equality for PLHIV and outlines the legal framework for providing HIV services in the country. Further, the project collaborated with local NGOs to establish five legal clinics and a hotline to help PLHIV understand, use, and protect their rights under the new law.

The Health Policy Initiative also provided assistance in overcoming barriers to effective policy implementation. Through work with PLHIV and MARPs, the project helped identify the ways in which stigma and discrimination hinder achievement of program goals; and then worked with multisectoral partners to devise appropriate solutions. For example, the project supported in-country partners to assess stigma and discrimination in healthcare settings in Kenya and Ukraine and promote dialogue on recommended next steps.

Measuring and Monitoring HIV Stigma

Program planners must operationalize stigma-reduction initiatives and assess whether these interventions are succeeding in reducing stigma and discrimination—as these are significant barriers to achieving program goals, averting the spread of HIV, and improving the lives of those affected by the epidemic. Although progress has been made in developing programs to reduce stigma and discrimination, lack of standardized indicators for measuring their effectiveness has inhibited application and scale-up of proven strategies.

STIGMA INDICATORS

The Health Policy Initiative participated in expert working groups to build consensus around key areas of stigma requiring action; identify gaps in stigma measurement; and agree on testing strategies. Existing measures and measurement tools were collected in 2009 and, since then, efforts have been underway to consolidate measures and tools and begin to develop a way forward. International partners agreed to measure three main areas of stigma: community level, facility/provider level, and PLHIV. The Health Policy Initiative took the lead to develop the Health Facility and Provider Stigma Measurement Tool. To share promising practices and lessons learned in stigma measurement and stigma reduction, partners also launched the new Stigma Action Network (www.stigmaactionnetwork.org).

HEALTH FACILITY AND PROVIDER STIGMA MEASUREMENT

Research has shown that three main causes of HIV stigma prevail in healthcare settings: (1) insufficient
awareness by health providers about what stigma looks like and its consequences; (2) fear around HIV transmission in the workplace; and (3) attitudes that associate HIV with perceived immoral behaviors. Over time, interventions targeting each of these drivers can effectively reduce HIV stigma and discrimination.

The Health Policy Initiative supported three field studies to test indicators and questions regarding HIV-related stigma and discrimination at the health facility and provider level. The Health Facility and Provider Stigma Measurement Tool validated previous field tests that assessed HIV stigma and discrimination in healthcare settings, including items that assessed providers’ fear of HIV transmission and attitudes of shame and blame associated with perceived immoral and improper behaviors of HIV-positive people.

CITIZEN MONITORING MODEL

The Health Policy Initiative piloted a citizen monitoring model with national networks of PLHIV to enhance their capacity to observe, gather, and analyze evidence and advocate by using evidence to influence decisionmakers and opinion leaders to make positive changes. Citizen monitoring is especially important for MARPs and other disenfranchised groups that are often under- or inadequately represented in policy decisionmaking. Networks of PLHIV in Vietnam and Mali were empowered to carry out participatory monitoring activities to further evidence-based policy advocacy and dialogue. These groups are now using the evidence to advocate for improvements in HIV services, including reducing stigma- and discrimination-related practices.

STIGMA ACTION NETWORK

The Stigma Action Network can be accessed at www.stigmaactionnetwork.org. This site is the first step in the formation of a global network that will allow people involved in program design, research, and advocacy on HIV stigma and discrimination to share information, tools, and experiences.

REFERENCES


The project’s stigma-related publications are available online at www.healthpolicyinitiative.com. Illustrative materials are listed below.

- Stigmatization and Discrimination of HIV-Positive People by Providers of General Medical Services in Ukraine (2007)

ONLINE COURSE

The Health Policy Initiative’s course on “HIV Stigma and Discrimination” can be accessed online at www.globalhealthlearning.org.

PROJECT RESOURCES

The project’s stigma-related publications are available online at www.healthpolicyinitiative.com. Illustrative materials are listed below.

- Stigmatization and Discrimination of HIV-Positive People by Providers of General Medical Services in Ukraine (2007)

The USAID | Health Policy Initiative, Task Order 1, is funded by the U.S. Agency for International Development under contract GPO-1-01-05-00040-00, beginning September 30, 2005. HIV activities under the initiative are supported by the President’s Emergency Plan for AIDS Relief. Task Order 1 is implemented by Futures Group, in collaboration with the Centre for Development and Population Activities (CEDPA), White Ribbon Alliance for Safe Motherhood (WRA), and Futures Institute. To learn more, please contact:

Futures Group
Health Policy Initiative
One Thomas Circle, NW, Suite 200
Washington, DC 20005 USA
Tel: (202) 775-9680
Email: policyinfo@futuresgroup.com