Stigma and HIV/AIDS—A Pervasive Issue

The issue.

Stigma looms large and ominous, shadowing the HIV/AIDS pandemic. It relates to every HIV intervention, including general prevention, the prevention of mother-to-child transmission, anti-retroviral treatment, and care and support for the patient and family, including children. On an institutional level, stigma plays a major role, affecting the ability of public health workers to prevent infection, to treat and to help people living with HIV/AIDS, and to assist loved ones in managing and coping with the condition. On a personal level, stigma can mean loneliness, abandonment, ostracism, violence, starvation, and death.

We are just beginning to realize the scope of what Dr. Jonathon Mann, who headed the World Health Organization Global Programme on AIDS, described in 1987 as “the epidemic of stigma, discrimination, and denial...the third phase of the disease that is as central to the AIDS challenge as the disease itself.”

What is stigma?

Stigma is a complex social phenomenon or process that results in a powerful and discrediting social label and/or radically changes the way individuals view themselves and are viewed by others. Stigma can be experienced internally (self-stigma) or externally (as in discrimination). Internal stigma can lead to a person’s unwillingness to seek help or to access resources. External stigma can lead to discrimination based on one’s perceived or actual HIV-positive status or on one’s association with someone else with perceived or actual HIV-positive status.
Stigma and disease have been common companions throughout human history—the classic example being the extreme stigma experienced by persons with leprosy that has persisted long after the discovery of a cure. The causes of stigma vary from society to society, but usually stem from practical, moral, economic, cultural, and political factors. Specific causes of HIV/AIDS stigma may include: lack of knowledge or confusion about HIV/AIDS prevention, transmission, or treatment; traditional or religious beliefs about sickness and death; judgmental attitudes about the lifestyles of those affected by HIV/AIDS; and fear. Stigma may also reinforce existing inequities. For example, members of already marginalized or excluded groups—such as sex workers, resource-poor single women, and members of the lower class or caste—who become infected with HIV may experience greater stigma than others.

Why is it important?

HIV/AIDS-related stigma is important because it frequently shatters infected persons’ identity and self-confidence, significantly decreasing their ability to manage the disease successfully. Stigma can also impede health workers’ capacity to implement and make progress on HIV/AIDS interventions by lowering the demand for prevention information and HIV counseling and testing services, and by discouraging timely health-care-seeking behavior for care and support. In practice, stigma may also affect a person’s willingness to adopt HIV/AIDS risk-reduction behaviors, such as the use of condoms. Pregnant women who are HIV-positive may be unwilling to accept treatment to reduce the risk of infection in their unborn children, or may reject care and treatment that would benefit them and other family members. Stigma can discourage sexually active youth and others at risk from seeking HIV counseling and testing, or prevent people who test positive for HIV from seeking psychosocial and physical support from family and friends. In addition, stigma can curb health workers’ ability to provide appropriate, good-quality clinical health services, and can undermine food and economic security, if HIV-positive people are dismissed from employment, shunned as shop owners or vendors, banned from use of land for farming, or banned from use of common resources, such as communal water supplies. Stigma can also limit HIV-positive people’s participation in important social events, such as weddings, naming ceremonies, and other significant community and family celebrations.

The categorized list on page 3 illustrates the potential effects of stigma on individuals, communities, and health program interventions.

In short, because of its pervasive presence, we cannot begin to meet the challenges of HIV/AIDS without dealing with stigma at the personal, community, and formal institutional level.

What is known about stigma?

We know that, worldwide, stigma has accompanied HIV/AIDS since the condition was first identified. We recognize that stigma can act as a barrier to care and treatment and can be more painful than the disease itself. Since the 1990s, health professionals and sociologists have created and refined stigma definitions and proposed frameworks for categorizing and analyzing stigma. We can only validate progress in reducing stigma, however, by first defining how to measure it.
Effect on the individual and/or community

- Emotional stress and anxiety, depression, attempted suicide, isolation
- Problems in family relationships and friendships
- Increased inequities between those who are affected and those who are not
- Increased disability
- Concealment of the disease after diagnosis, leading to stress and anxiety
- Poor prognosis
- Participation restrictions (e.g., loss of job, economic dependency, inability to marry, lack of access to loans and credit) that may affect entire families and, in high prevalence areas, entire villages
- Isolation
- Increased psychological and psychiatric morbidity
- Lack of motivation to continue treatment
- Empowerment (e.g., positive self-image and confidence) developed in resistance to discrimination (through participation in support groups for people living with HIV/AIDS)

Effect on health program interventions

- Delay in presentation for treatment leading to prolonged transmission of the disease in the community
- Poorer treatment prognosis; more complicated and more expensive treatment
- Continued transmission of HIV
- Poor adherence and default on treatment
- Risk of drug resistance
- Increased burden on health services
- Negative image of health program

Nigeria

Quantitative and qualitative data demonstrate that there are high levels of stigma and discrimination within the general population. The U.S. government is working to increase awareness of the value of HIV/AIDS testing and the prevention of mother-to-child transmission as part of responsible planning for and parenting healthy children. The program hopes to decrease the stigma associated with its services and to increase the uptake of parents volunteering for counseling and testing.

How can HIV stigma be measured?

We have begun to realize the profound effect that stigma has on HIV/AIDS prevention and treatment, and we have started to address it programmatically. But we have not yet been successful in learning the best way to measure its prevalence or to track changes as a result of program interventions. Although stigma reduction is now a key objective of many programs of health education, individual and community empowerment, and socioeconomic rehabilitation, accurate evaluation of these interventions remains challenging due to a lack of instruments to measure stigma and discrimination. Indicators are needed to assess country situations, to monitor changes and progress during project implementation, and to provide
tangible evidence for evaluation of the outcomes and impact of our efforts. Fortunately, several organizations are making progress in measuring and prioritizing the importance of stigma.

In South Africa, for example, staff at the Siyam’kela Project recently conducted a comprehensive participatory study on stigma with the main goal of establishing appropriate, measurable indicators of HIV/AIDS stigma. They worked with people living with HIV/AIDS, national health system staff, private company managers, and a diverse representation of community members (male, female, white, black, persons of mixed heritage and different economic levels, and persons from various geographic areas) to produce a set of stigma indicators that might work for South Africa and be adapted elsewhere. Their 12 indicators are divided into two categories for measuring stigma: internal (e.g., self-exclusion from services and opportunities, social withdrawal, and fear of disclosure) and external (e.g., avoidance, rejection, and abuse).6

**Can disease-related stigma measurement be standardized?**

HIV/AIDS health workers can benefit from experiences with stigma measurement for other, “older” diseases, such as leprosy, buruli ulcer, and epilepsy. There is extensive historical documentation of the damage stigma can do to people living with these diseases and to their relatives and caregivers. In the Netherlands, a staff member at the Royal Tropical Institute (KIT) is leading an effort to create a standardized set of indicators that measures stigma across diseases. The idea is that because stigma seems to manifest itself similarly in all diseases, one universal set of indicators could be used to measure stigma prevalence as well as change over time. KIT colleagues have conducted extensive literature reviews for stigma measurement attempts in leprosy7 and are organizing a conference with the Swiss Tropical Institute to discuss standardized stigma indicators in December 2004.8

**Challenges**

Three notable challenges to addressing HIV/AIDS stigma reduction exist: (1) Health care workers may perpetuate HIV/AIDS-related stigma during testing, counseling, prevention of mother-to-child transmission, and provision of care, (2) People living with HIV/AIDS may become severely demoralized and depressed (especially those who already experience stigma for other reasons, such as sexual orientation), (3) Program staff may be overwhelmed by long-held societal beliefs about disease (and the need to protect society from those infected by it), and by other internal and external stigma that permeate individuals, communities, and institutions.

**Ivory Coast and Zambia**

Country teams in Ivory Coast and Zambia have identified shining examples of people living positively with HIV/AIDS—two dynamic women who have helped break down societal stigma by disclosing their HIV status, educating others on HIV/AIDS facts, and persuading others to seek counseling and testing. The story of these women underscores the notion that not only are people living with HIV/AIDS often the best authorities on stigma, but they may also be in the best position to help dispel it.
Stigma perpetuated by health care workers and systems

The stigma surrounding HIV/AIDS is an all-pervasive challenge that can be exacerbated by both the intentional and unintentional behavior of health care professionals and staff as well as by health service record keeping. Rejection of those who are HIV-positive or are perceived to be HIV-positive can occur between couples; within extended families, communities, and workplaces; at international borders; and even in health care settings. For persons with HIV/AIDS, experiencing such discrimination can be devastating—emotionally, socially, and physically. Health care workers—even those who have had training as counselors—may experience difficulty conveying a positive HIV test result or providing appropriate counseling and social service referral. They may mark medical records as HIV-positive or use a symbol that is known to mean HIV-positive (for example, a red sticker or red folder). They also may disclose a person’s HIV-positive status to family, friends, community members, or superiors without permission. Training staff in stigma-awareness, setting standards of behavior, supervising performance, and linking good response to rewards, best address these behaviors.

Stigma of the already stigmatized

HIV/AIDS stigma has been found to be more challenging for groups that have a preexisting stigma. In India, for example, lower-caste women who test positive for HIV are likely to experience more stigma than lower-caste HIV-positive men. In South Africa, with its racially divided history, research reveals that HIV is associated with darker skin color. HIV/AIDS is seen as “a [black] African disease.” Further, women who attend antenatal care facilities are routinely tested for HIV as part of services targeting prevention of mother-to-child transmission. So HIV/AIDS is thought by many South Africans to be an “African woman’s disease.” This is a particularly serious manifestation of stigma because it may lead white or lighter-skinned South Africans to assume they are not at risk. It also pins a damaging label on black South African women, which can lead to discrimination, gender violence, and other forms of stigma.

Overcoming stigma bit by bit

Because stigma is deeply embedded in many societies and cultural beliefs, it may seem impossible to “eliminate” it. Successful stigma reduction may therefore require the use of a comprehensive set of interventions focused on prevention, care, support, and treatment. Some types of interventions, however, will have greater effects than others. For example, Basketball Hall of Famer Magic Johnson’s decision to disclose his HIV-positive status, along with his participation in education campaigns, has had a profound impact on stigma against people living with HIV/AIDS in the United States. Similarly, community empowerment in Uganda, along with increased openness about HIV, has contributed to the acclaimed decline in HIV prevalence and incidence there.

Tanzania

Efforts are being made in Tanzania to decrease stigma through an outreach group and a youth campaign called “ISHI” (which means “live” in Swahili). The outreach group includes 470 traditional birth attendants and 100 health care providers who help mothers living with HIV/AIDS by providing them with nevirapine and referring them to support services. Phase II of the ISHI campaign, launched in March 2004, will encourage open communication about HIV among youth, using an approach adapted to and focused on Tanzanian cultural values.
Stigma prioritized on the international health agenda

There is now international recognition of the importance of stigma. At the XIV International AIDS Conference in Barcelona, July 2002, USAID’s session on stigma and discrimination was its best-attended session. UNAIDS made stigma reduction the theme of the 2002 and 2003 World AIDS Days. And bilateral, multinational, and private donors are starting to support more focused, integrated stigma programming in recognition of its importance in services uptake and individual human rights.

Many churches and other faith-based organizations have declared their intention to work for the eradication of stigma and discrimination by raising awareness of factual information related to HIV/AIDS transmission and prevention; working in partnership with public health workers and their local communities; and embracing persons living with HIV/AIDS with care, support, and compassion. The Ecumenical Advocacy Alliance has produced two awareness-raising and guiding documents for faith-based organizations—Church Leadership & HIV/AIDS: The New Commitment and Church, AIDS, & Stigma.

The different groups of people living with HIV/AIDS are also providing momentum to reduce stigma and discrimination. Because people who actually experience HIV-related stigma are the best source for understanding stigma, its effects, and its evolution as the epidemic changes, people living with HIV/AIDS have provided feedback and contributed to research on stigma and the design of interventions. Organizations such as UNAIDS, which has produced fact sheets, reports, and guidance on stigma, are also contributing to this effort.

Ethiopia

Through efforts to implement projects targeting the prevention of mother-to-child transmission, Ethiopia has learned that stigma is the largest challenge that women face outside the health center. The Hareg Project is working to create solid links in the community to alleviate stigma while strengthening existing maternal and child health services.

Practical tools to address stigma

New, practical, HIV-related stigma tools include a participatory educational toolkit for use with communities and other groups, and a training manual for health care workers. Another importance resource targeted toward HIV/AIDS program managers working at nongovernmental organizations, communities, and health educators has been produced by the Academy for Educational Development (AED), The Manoff Group, and the International Center for Research on Women (ICRW), with USAID funding. Based on extensive stigma research conducted by ICRW and its partners in Zambia, Tanzania, and Ethiopia, Understanding and Challenging HIV Stigma: A Toolkit for Action is a practical resource with specific suggestions and guidance on developing stigma-reduction messages and activities that can be adapted to different country and community contexts. The toolkit annexes contain sample exercises (125 in all), timetables, pictures, and fact sheets.

EngenderHealth, with USAID funding, produced two stigma-reduction manuals for health workers. One manual is for trainers; the other is for participants and includes an infection-prevention booklet for health care providers. These manuals go to the heart of the reasons health workers may stigmatize others or be
targets of stigma themselves. The manual addresses the causes of stigma and encourages health workers to empower themselves through knowledge and locally available resources.\textsuperscript{15}

\textit{Intervention ideas to address stigma}

Even with imperfect knowledge, we can suggest courses of action based on lessons learned from early observations of progress.

- Support qualitative and quantitative research efforts focused on stigma, and disseminate the results widely.
- Incorporate monitoring and evaluation of stigma in activity implementation.
- Involve people living with HIV/AIDS in stigma research and program design and evaluation.
- Empower communities to address stigma through awareness of accurate and updated information about HIV/AIDS and accompanying stigma.
- Integrate and/or mainstream HIV prevention, care, treatment, and support activities into existing programs and facilities whenever possible.
- Encourage a variety of institutional activities related to stigma—multilateral, bilateral, international, and local nongovernmental organizations, businesses, and faith-based organizations.
- Promote legal and policy environments that keep stigma and discrimination in check.
- Develop more practical tools for understanding and addressing stigma.
- Incorporate activities for factual information-sharing and individual and group counseling.
- Create an environment that promotes stigma reduction within health care facilities, i.e., one that includes training, sensitization, and performance standards.

\textbf{Rules of thumb when developing HIV/AIDS stigma-reduction strategies:}

- Always involve people living with HIV/AIDS in community-, district-, and national-level issues, solutions, and policy development.
- Always avoid reference to victim personae; for example, do not use labels or stigmatizing language, such as “AIDS victim.”

\textbf{Links}

Stigma Toolkit—Participatory Educational Exercises  
http://www.changeproject.org/technical/hivaid/stigma.html

Stigma Training Manual for Health Care Workers  
http://www.engenderhealth.org/res/offc/hiv/ stigma/

Stigma and Indicators  
http://www.policyproject.com/siyamkela.cfm

Health and Development Networks eForum on Stigma  
http://www.hdnet.org
Endnotes


