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A CLOSER LOOK: THE INTERNALIZATION OF STIGMA RELATED TO HIV

A man in Mexico is fired after he develops tuberculosis and fellow workers fear that he may be HIV-positive. A pregnant woman in Ukraine learns of her HIV status during delivery and healthcare workers coerce her into being sterilized after giving birth. In Cambodia, community members avoid the local temple when the monks there begin providing support to AIDS orphans. In-laws steal a woman's property in Kenya after her husband dies of an AIDS-related illness and she is blamed for bringing HIV into the household. HIV-positive injection drug users (IDUs) are denied access to antiretrovirals (ARVs) in Vietnam because they are perceived as not being good candidates to adhere to treatment regimens. In South Africa, a woman is stoned to death when she discloses her HIV status.

These are examples of stigma and discrimination that are all too common for people living with HIV, other

vulnerable groups, and their families and caregivers. They represent “external” or “enacted” stigma and are the types of experiences that may first come to mind when we think of HIV-related stigma and discrimination. External stigma is rooted mainly in fear and judgment of what is different, leading to blame, distancing, and discrimination. It is an attempt to promote social order but, ironically, it breaks down communities.

There is another dimension of stigma that has received less attention from researchers and program planners. “Internal stigma”—also described as felt, imagined, or self stigma—is the product of the internalization of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV-positive. It can affect caregivers and family members, who also may internalize feelings of shame, guilt, or fear. Internal stigma can have a profound effect on HIV prevention, treatment, and care. For example, an

HIV-positive mother in India continues to breastfeed her child because failing to do so may cause family and community members to suspect her HIV status. A man in Botswana, having internalized the notion that equates AIDS with death, does not take part in the country's national ARV treatment program. A Cambodian sex worker does not visit the clinic regularly to treat sexually transmitted infections (STIs) because she fears blame and judgment from clinic staff. A couple in Haiti, both living with HIV and too ashamed to disclose their status, delay making future plans for the care and support of their children. Internal stigma, like external stigma, breaks down families and communities.

In recognition of this destructive impact and the gaps in prevailing responses, the USAID-funded POLICY Project has made measuring and mitigating internal stigma a cornerstone of its stigma and discrimination work.

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POLICY'S FLAGSHIP STIGMA AND DISCRIMINATION INITIATIVES: SIYAM'KELA AND MO KEXTEYA

The construction of stigma, whether internal or external, is facilitated by social processes and institutions in a particular society—for example, education and health systems, government policies and laws, the media, faith-based organizations, the family, and cultural organizations and movements. For this reason, POLICY and its partners embarked on two initiatives to study HIV-related stigma and develop guidelines for mitigating its impact in various sectors (see Table 1). During Phase 1, a key objective was to design indicators that can be used by program planners to measure stigma and discrimination, as well as

evaluate the impact of mitigation efforts (for examples, see Table 2 on p. 13).

The Siyam'kela Project focused on three key areas that it believed could challenge stigma in South Africa: faith-based organizations and communities; government workplaces; and the relationship between media and people living with HIV. Similarly, the Mo Kexteya Project, based in Mexico, focused on public policy and legislation, healthcare settings, people living with HIV, and the media.

INTERNAL STIGMA: A CLOSER LOOK

Internal stigma is intrinsically linked with external stigma, as the fear of judgment or discrimination from

others can profoundly influence the way in which people living with HIV view themselves and cope with their HIV status. The process of internalizing stigma is complex, and any person diagnosed as HIV-positive experiences some form of it. Psychologists suggest that internal stigma is shaped by previous experiences of shame and blame. It is normal to go through various stages in processing internalized stigma, and most individuals will reach a point of acceptance, having worked through some of their negative feelings and highlighted their positive attributes.

There is evidence to suggest that individuals who experience high levels of internal stigma do so in the context of a recent diagnosis, have

WHAT IS HIV-RELATED STIGMA?

Stigma is defined as an attribute or quality that “significantly discredits” an individual in the eyes of others. Stigma is a process and occurs within a particular culture or setting—certain attributes are seized upon and defined by others as discreditable or unworthy (UNAIDS, 2002). The stigmatized person is, therefore, seen to possess a spoiled or polluted identity that deviates from social norms and which deserves sanctioning (Goffman, 1963, qtd. in UNAIDS, 2002). Stigma is not unique to HIV and has been seen throughout history in relation to other diseases, including tuberculosis, syphilis, and leprosy, which are associated with the transgression of social norms. HIV has been stigmatized because it can be fatal and therefore causes fear; it is often associated with

behavior that is already stigmatized, such as sex work; infection is seen as the result of “choices” made by an individual (e.g., the “choices” to have unprotected sex or to share needles to inject drugs); and it is seen as punishment for “deviant” behavior (Bollinger, 2002).

Current understandings go beyond explaining stigma in terms of individual psychology to see it as socially constructed. The process of stigmatizing a person may involve the following steps: differences (such as HIV status) are noted and labeled; these differences are then given a negative attribute; a distinction is made between “us” who do not have this negative attribute and “them” who do; the person with this negative attribute is seen as

having a lower status; and, finally, this person is discriminated against (Link and Phelan, 2001).

Stigma thus operates by producing and reproducing social structures of power, hierarchy, class, and exclusion and by transforming difference—such as class, race, ethnicity, health status, sexual orientation, and gender—into inequality (International Center for Research on Women, 2002). So the stigma attached to HIV as an illness is layered upon pre-existing stigma (Herek and Glunt, 1988, qtd. in Busza, 1999). Stigma serves various social and psychological functions: it serves to distance the individual or group from the fear of infection by facilitating denial of risk and promoting a sense of invulnerability; it

maintains social order by marginalizing the “undesirable”; it reinforces social norms around fidelity and family by moralizing around “promiscuity” and other “deviant” behavior; and it may be a strategy in resource-poor countries for families and communities to exclude those who are perceived as a drain on limited resources in that group (Stein, 2003). With particular reference to the function of stigma in a society, then, stigma can be seen as *instrumental*, arising from utilitarian self interest, or *symbolic*, arising from a value-based ideology. Instrumental stigma allows people to distance themselves from the fear of infection, and symbolic stigma is based on moral judgments (Herek and Capitanio, 1993, qtd. in Stein, 2003).

TABLE I. FLAGSHIP STIGMA MITIGATION INITIATIVES OF THE POLICY PROJECT AND ITS PARTNERS (PHASE I—FORMATIVE RESEARCH)*

	SIYAM’KELA (SOUTH AFRICA)	MO KEXTEYA (MEXICO)
Project Name	<ul style="list-style-type: none"> ▪ Nguni word, meaning “we are accepting” or “together we stand” ▪ Emphasizes unity and compassion 	<ul style="list-style-type: none"> ▪ Náhuatl language of Aztecs, connotes similarity and comparability, or as a verb, “to appear” or “to change” ▪ Emphasizes commonalities and increased visibility
Focus Areas	<ul style="list-style-type: none"> ▪ People living with HIV and the media ▪ Government workplaces ▪ Faith-based organizations 	<ul style="list-style-type: none"> ▪ People living with HIV and the media ▪ Government laws and policy ▪ Healthcare sector ▪ Workplaces and labor unions
Methods	<ul style="list-style-type: none"> ▪ Perceptions and experiences were gathered from 182 participants (23 focus groups, 11 in-depth interviews) ▪ Process guided and informed by two expert workshops on indicator development; meetings of four reference groups; and seven telephone interviews with HIV experts as a form of quality control ▪ Literature review on stigma ▪ Media scan 	<ul style="list-style-type: none"> ▪ Qualitative and participatory research with people living with HIV ▪ Qualitative and quantitative research into barriers to access to and use of healthcare services ▪ Review of legislation, policies, norms, and advocacy techniques related to stigma and discrimination ▪ Monitoring of print media
Outputs	<ul style="list-style-type: none"> ▪ Documentation that provides both theoretical and contextual analyses of HIV-related stigma ▪ Indicators of internal and external stigma ▪ Guidelines and promising practices to assist in the development of interventions to mitigate HIV-related stigma ▪ Development of stigma reduction training materials ▪ Testing of training programs for people living with HIV working in communities ▪ Development and testing of a media training program 	<ul style="list-style-type: none"> ▪ Project report and conceptual framework for response ▪ Stigma indicators guide ▪ Adaptation, development, and testing of training programs for healthcare providers ▪ Project on improving monitoring and advocacy activities related to stigma, discrimination, and the promotion of promising practices in legislation, policies, and norms ▪ Preparation of policy dialogue and stigma reduction materials ▪ Development and testing of a media training program ▪ Creation of a photojournal on people living with HIV
Partners	<ul style="list-style-type: none"> ▪ POLICY Project ▪ USAID ▪ Chief Directorate: HIV/AIDS and TB, National Department of Health ▪ Centre for the Study of AIDS, University of Pretoria ▪ Insideout 	<ul style="list-style-type: none"> ▪ POLICY Project ▪ USAID ▪ National Institute for Public Health (INSP) ▪ National AIDS Program for Mexico (CENSIDA) ▪ Colectivo Sol ▪ Red Mexicana de Personas Viviendo con VIH/SIDA ▪ Frente Nacional de Personas Afectados por HIV (FRENPAVIH) ▪ Letra S ▪ Medilex

* Note: Each project is in Phase II, the implementation phase. In this phase, stigma and discrimination mitigation strategies are being conducted in specific sectors. This phase allows for refinement of the indicators and promising approaches identified during the research phase, evaluation of the effectiveness of the approaches used, and creation of replicable best practices and models for reducing the impact of stigma and discrimination on the uptake of prevention, treatment, and care services.

families who are less accepting of their illness, are less likely to have attended an HIV-positive support group, and know fewer people affected. These individuals also may be more worried about spreading infection to others (Lee et al., 2002). In other words, isolation may promote internalized stigma because the individual is unable to have supportive experiences that are positive and that help to build self-esteem and self efficacy. One U.S. study found that internal stigma contributes significantly to levels of depression, anxiety, and hopelessness in people living with HIV (Lee et al., 2002).

One way of understanding internal stigma, then, is to see it as being a result of complex interactions between *social* factors (including the economic, cultural, and political landscapes; access to prevention and care services; community support networks; sources of information; and, of course, prevailing levels of stigma and discrimination); *contextual* factors (including the circumstances and conditions of a person's life; use of alcohol or drugs; power relations between those living with HIV and their partners and families; living conditions; time since diagnosis; and family circumstances); and *self* factors (including mood states such as depression and anxiety; belief or meaning systems; coping skills and resilience; levels of knowledge; life experience and life skills; and self-esteem and self awareness).

Who Experiences Internal Stigma?

The primary targets of HIV-related stigma are individuals living with HIV and/or those who are perceived to be HIV-positive or associated with HIV.

“Internal” or “felt” stigma refers to the personal shame associated with HIV/AIDS and the fear of being discriminated against on account of the illness. Discrimination or “external” stigma refers to any measure entailing any arbitrary distinction among persons because of their confirmed or suspected HIV status or state of health.

For example, associations may be made if an individual is a sex worker or an IDU. Association also can be made on the basis of sexual orientation, specifically with men who have sex with men (MSM). Other associations may be made as a result of physical appearance. One South African study found that community members who had lost weight, experienced hair loss, had a cough, had body or facial sores, or showed changes in complexion were assumed to be HIV-positive and were stigmatized (Centre for the Study of AIDS, 2004). In Mexico, a Mo Kexteya study among health workers found that people with tattoos were assumed to be HIV-positive.

Internal stigma can disempower people living with HIV—individuals may blame themselves for their experiences with stigma, even to the point where they cease to assert their right to treatment and other social benefits. HIV-positive people who accept society's negative characterizations may blame themselves for the intolerance of others, feeling that they deserve mistreatment (Herek et al., 1998).

The secondary targets of HIV-related stigma include the partners, family members, friends, professionals, and

volunteers associated with affected groups. Using Goffman's terminology, these individuals experience a “courtesy stigma” through their close association with HIV. Secondary stigma may leave people living with HIV without support, takes a toll on those who work with affected groups, and may deter professionals and volunteers and make their work more difficult and stressful (Herek et al., 1998). In a Mo Kexteya study, health professionals reported that male doctors sometimes avoid HIV-related medical specializations for fear of being associated with homosexuality. Those who experience secondary stigma may thus internalize the shame and guilt associated with HIV. This may be particularly true for those who are closer to the person living with HIV; for example a parent might feel she or he had not raised a son or daughter with the “appropriate” morals.

How Does Internal Stigma Affect Individuals?

The findings of POLICY's work in this area suggest five key categories for consideration.

1. Process of internalizing stigma and loss of control. When the physical and environmental context in

which the person lives includes high levels of denigration and prejudice, people living with HIV often experience a sense of loss of control.

Contributing to this sense of loss of control are pressures related to costs, job security, other social pressures, and facing or experiencing physical deterioration. For example, in Mexico, this sense of loss of control or direction accompanied accepting or internalizing the stigma related to HIV and resulted in feelings of negativity, inferiority, and a basic discomfort with oneself and one's life.

2. Perception of self. Some people living with HIV felt they had disappointed others and had brought shame on their families and community. One South African female participant said, "I was feeling the fear that I disappointed those people at church and then I decided no, the right approach was to disclose" (POLICY Project et al., 2003a, p. 21). Many participants reported deep-seated feelings of guilt, self blame, and anguish about being HIV-positive. Some people see themselves as tainted and fear infecting others. They also may exhibit profound anxieties about death and dying. A Mexican male participant recalled, "It took a lot of effort to learn to live with HIV and keep on with my life" (National Institute of Public Health et al., 2004, p. 7). In addition, the Mexico study found that self blame was accompanied by other deep fears which an HIV diagnosis evoked: fear of hurting others and the fear of causing pain and suffering to others. These fears point to a damaged sense of self common in people living with HIV.

3. Self-protective action. In both the Mexico and South Africa projects, there were a number of distinct

manifestations of self-protective action or mechanisms to protect oneself from hurt and discrimination:

- **Self exclusion:** Many people living with HIV would exclude themselves from services and opportunities. These included health clinics, support groups, and material assistance programs. As one South African male participant noted, "Even if there is an offer of a job, I would not apply. It is hard because you think that they will draw blood or look at your urine and see that something is wrong" (POLICY Project et al., 2003a, p. 20).
- **Subterfuge:** Internal stigma can lead affected individuals to police their own behavior and discourse, either to avoid being stigmatized or to prevent their HIV status from becoming known to others. Hiding or misleading others as to one's HIV status or sexual orientation was noted in the Mexico study. In South Africa, some participants recalled telling neighbors that they suffered from anemia to avoid having to disclose HIV status.
- **Avoidance:** In some cases, internal stigma results in an individual's avoidance of particular settings, such as community-based associations to assist people living with HIV (Monico et al., 2001). In this way, opportunities may be lost to manage sexual and reproductive health, as well as HIV wellness. Other forms of avoidance seen in Mexico included avoiding making long-term plans and avoiding social and family activities.
- **Social withdrawal:** This kind of self-imposed isolation led some people to exclude themselves from sexual and loving relationships.

One South African man said, "Although I've accepted the virus myself, the thing is I don't want anyone next to me" (POLICY Project et al., 2003a, p. 21). This participant's response highlights the insidiousness of internal stigma—while he had reached a point of self acceptance, he was unable to contemplate a loving relationship because he did not feel worthy. This also was noted for participants in the Mexico project where avoidance of relationships was reported. As one participant said, "When I learned that I had HIV, I cut myself off from the world, because I felt bad about myself. I locked myself in the house, I didn't answer the phone; all day I slept" (Letra S et al., 2004).

- **Continuing risk behavior:** Some individuals also may fail to change their risk behavior for fear that such change would arouse suspicion and stigma. For example, internal stigma may lead HIV-positive nursing mothers who are aware of their status to breastfeed, despite the dangers of transmission to the child, because of fear of the revelation of HIV status arising from bottle feeding.

4. Overcompensation. Some participants said they felt a need to prove to their faith congregations that they were "good" people by attending church regularly. Said one South African female participant, "For me, I would say that earlier I thought I was doing what I thought was godly. I was doing my best to serve God. But when I found out that I was HIV-positive I said no, I think it was not enough" (POLICY Project et al., 2003a, p. 22). Some participants in focus groups commented that they felt a need to

work harder than their colleagues to prove that they could still make a contribution even if they were HIV-positive, sometimes to the detriment of their health.

5. Fear of disclosure. Most participants reported that disclosing their status was very difficult because of the fear of judgment and rejection. One South African woman said: “Some [people living with HIV] just cannot find it in themselves to disclose because of the stigma that might follow. They just have so much to lose—the respect of their community and family. Their friends will reject them. So they live in silence. It is an enormous burden to be scared of stigma” (POLICY Project et al., 2003a, p. 22). Participants in the Mexico study also noted that the fear of being discovered was widespread. An HIV-positive male participant from Mexico said, “Living with HIV causes a confusion related to death and sexuality—so people come and tell you ‘you’re gonna die’ and you have to live with that stigma ... I have not been denied services yet but I live with the stigma of differentiated treatment” (National Institute of Public Health, 2004, p. 3).

Internal stigma, therefore, may lead people living with HIV to adopt a range of survival mechanisms to protect themselves from enacted stigma.

WHAT FACTORS INCREASE OR INHIBIT INTERNAL STIGMA?

Social Factors

As noted above, the broader political, cultural, and economic climates are key factors that influence internal stigma. HIV-related stigma (both internal and external) may be layered onto other forms of stigma and discrimination, such as racism and homophobia. For HIV-positive people who are from groups already marginalized and stigmatized, internal stigma may be heightened and more difficult to come to terms with.

- **Gender constructions.** HIV-related stigma interacts with existing cultural prejudices. When women become infected with HIV or develop AIDS, their already disadvantaged status may subject them to differential treatment by society. For example, in the United States, although women were one of the fastest growing sectors of people living with HIV in the early 1990s, gender issues interacted with HIV-related stigma to make them one of the most invisible affected groups at the time (Herek et al., 1998). Participants in the Siyam’kela study mentioned the perception in South Africa that HIV/AIDS is a woman’s disease. Women in South Africa are regularly blamed for STIs, moral decay, and other social ills. Patriarchy has ensured that many women feel as if they are second-class citizens. If a woman has internalized such a view of herself, it is possible that she may be predisposed to think of her HIV status as reinforcing this second-class status. Some female participants in the

study mentioned being called “bitch” and “prostitute” when they disclosed their HIV status.

- **Homophobia.** Internalized homophobia is a well recognized phenomenon in gay men and lesbians who have internalized negative attitudes toward or discomfort with their sexual orientation. In Mexico, for example, HIV is often equated with homosexuality, and homosexuality with social deviation. Many MSM living with HIV report that they believe they acquired HIV because they are gay. In other words, they accept the belief that it is their sexual orientation that caused their infection; this adds to their shame about being HIV-positive and may revive feelings of previously felt shame and anxiety.
- **Constructions of innocence and guilt.** How a person acquired HIV—through sex, rape, blood transfusions, injection drug use, medical accidents, or vertically—may have an impact on the shape and form of their internal stigma. Many of the Siyam’kela focus group participants reinforced this notion. According to participants, a person was considered “innocent” if they were passive or powerless in contracting HIV, for example through rape, being born to HIV-positive parents, or having blood accidents in health settings, and “guilty” if they contracted HIV sexually outside of marriage or through injection drug use. In light of this, it is likely that internal stigma will be exacerbated by the views held by the person living with HIV on notions of innocence and guilt.

- **Race and class.** Participants in the Siyam’kela study made mention of the perception of HIV/AIDS as an African disease.¹ Because working class Africans are in the majority in South Africa, it is likely that their self image as black people would be positive. However, internalized racism is a real phenomenon and it is possible that some forms of internal stigma are reinforced by the damage done to the self-esteem of black people by apartheid.

Contextual Factors

- **A supportive environment.** One important factor is the environment in which people living with HIV operate; that is, whether it is supportive or hostile or is an environment where they feel they may be the only HIV-positive person. Focus group participants in the Siyam’kela study referred to a supportive environment as consisting of the support of family, partner, community, faith-based groups, and other community organizations and NGOs, like the National Association of People Living with HIV/AIDS, which they believed had an immense influence on overcoming internal stigma (POLICY Project et al., 2003a).
- **Power relations.** The relative power between a person living with HIV and his/her partner or family could influence the way in which that person experiences internal stigma. If the partner or family with more

power sends systematically negative messages, the relative impact of these messages is increased.

- **Living conditions.** In situations in which a person living with HIV is poor and dependent, or in which self efficacy is diminished and there is a reduced sense of control, it is likely that higher levels of internal stigma could manifest.

Self Factors

- **Health status.** Internal stigma may be easier to deal with if one is well, although it could be argued that increasing sickness could force a disclosure that might prove beneficial in the long run. The availability of ARVs is a crucial piece of this puzzle—as they become more widely available, there is a good chance that self-esteem can improve and self efficacy can be enhanced.
- **Self acceptance.** Many of the people living with HIV in the Siyam’kela study noted the importance of accepting their HIV-positive status. Most go through a process of moving from denial to acceptance. This may take time and may differ from person to person. In some instances, there may never be full acceptance. The degree of self acceptance may thus influence the development of internal stigma.
- **Spirituality/meaning system.** There is evidence to suggest that if people living with HIV are able to incorpo-

rate the experience of being positive into their meaning and belief systems, they are better able to cope and are happier. Conversely, experiencing one’s faith as punitive and judgmental is likely to add to internalized stigma.

- **Education level.** In South Africa, the poor and the under-educated are disproportionately represented in HIV statistics, although higher education does not in itself protect individuals from acquiring HIV. Where self-esteem and self efficacy are linked to education level, it is likely that the more education and information one has, the easier it may be to overcome internal stigma.
- **Resilience.** The Siyam’kela Project found that internal stigma was affected by an individual’s coping mechanisms. Some people cope with difficult life situations by withdrawing, while others will reach out and be more proactive and assertive. A South African man said, “But if you are weak and they look you in the eye and you just look away when you are telling them, they’ll jump on you, they will discriminate against you ... I think it has a lot to do with you as a person, if you’ve got the strength to look them in the eye” (POLICY Project et al., 2003a, p. 20). While resilience can be developed, like personality type, it is often an intrinsic quality in people.

1. In describing the fieldwork in South Africa, the Siyam’kela project adopted certain terms to reflect the relationship between race and HIV-related stigma. These terms are offensive to some as they are reminiscent of racial classification terms used in the apartheid era. Nevertheless, we have retained them to indicate our attempts to interview as diverse a range of South Africans as possible and to reflect the relationship between race and HIV-related stigma. Race and racism are ongoing themes in post-apartheid South Africa and race classification is still used by the current South African government. The terms are not rigid categories, but for the purposes of clarity we have adopted the following definitions: the term “black” refers to African, colored, and Indian South Africans; the term “African” refers mainly to black South Africans of indigenous origins. “White” refers mainly to South Africans of European descent. It is important to note that participants in the study may have their own idiosyncratic interpretation of these terms.

WHY IS IT IMPORTANT TO ADDRESS INTERNAL STIGMA?

External stigma can hinder access by people living with HIV to treatment, care, and support and diminish their participation in prevention. Likewise, internal stigma may deter people from disclosing their HIV status or cause them to avoid health facilities if they feel shame and guilt or fear rejection and ridicule. Their silence undermines treatment, care, and support efforts, as it affects their help-seeking behavior and they may not access services that could provide medical and social support. By addressing internal stigma, people living with HIV will be more confident role models and will be able to contribute to an improved socio-political environment.

It is thus crucial that addressing stigma be mainstreamed as a component of all HIV strategies. Internal stigma and *prevention* are linked because:

- Fear of stigma and discrimination may discourage people from accessing counseling and testing services.
- People living with HIV who have faced stigma and discrimination, and as a result been disempowered, may not be good role models for positive living. Thus, opportunities to challenge the “othering” associated with being HIV-positive may be lost.²
- People living with HIV who feel judged, have experienced discrimination, and have low self-esteem may feel less inclined or less able to practice safer sex.

- Many women living with HIV fear rejection, violence, and even death if they disclose to their partners. Their partners then may lose opportunities to test and prevent other infections and women may not access needed treatment and care services.
- Women who are HIV-positive may fail to access services for the prevention of mother-to-child transmission (PMTCT) because they fear blame, judgment, and discrimination. These same women may resist messages about breastfeeding alternatives because of the stigma associated with formula feeding (POLICY Project and Centre for the Study of AIDS, 2004).

To access ARVs, as well as treatment for opportunistic infections, people living with HIV need to come to terms with their internal stigma and feel confident that they will not experience rejection and discrimination in the healthcare system. For example, Botswana has embarked on a program to roll out ARVs, but the uptake has been slow. Similarly, the recent ARV roll out in South Africa has been characterized by low numbers. It is believed that stigma may be playing a role in both countries. Internal stigma and *treatment* are linked because:

- Many HIV-positive people wait too long to access treatment because they fear rejection and discrimination in healthcare settings (POLICY Project and Centre for the Study of AIDS, 2004).

- People living with HIV who come forward for treatment may have to disclose to their partners and families and may fear rejection and discrimination.
- Those on treatment may not adhere in order to avoid questions about their HIV status.

Care and support play an important role in ensuring quality of life for people living with HIV and, in many instances, prolonging life. An individual’s physical, mental, and spiritual health can be affected by attitudes of partners, family members, healthcare workers, and faith-based organizations. Internal stigma is linked to care and support because:

- People, usually women, who have experienced rejection from their partners, may fear accessing care and support services.
- Many people living with HIV face negative healthcare worker attitudes in care settings.
- Thus, they often turn to friends and family members, who are not adequately trained or equipped, for care and support.
- Caregivers, families, and partners may themselves find it difficult to seek help because they too have been stigmatized.
- Rejection by or of the family often means that the traditional support groups in the family have broken down and therefore more support from the state and NGOs is needed.
- Counseling usually is limited to pre-test and post-test counseling. Ongoing counseling is an ideal

2. “Othering” is a term used when a difference between people (such as HIV status) is noted and labeled, and this difference is then given a negative attribute. This creates a distinction between “us” (who do not have this negative attribute) and “them” (who do). The person with this negative attribute is seen as having a lower status.

opportunity to address internal stigma but ongoing counseling rarely happens, partly because of logistic constraints, but often due to attitudes towards people living with HIV.

- Faith-based organizations inadvertently may stigmatize HIV-positive people through interpretation of certain scriptures, thus affecting the relationships between people living with HIV and their carers (POLICY Project and Centre for the Study of AIDS, 2004).

From a *socio-political* perspective, addressing internal stigma will contribute to the development of a generation of people living with HIV who are strong and confident and able to act as positive role models. In addition, they can become involved in civil society organizations and social and political processes which can challenge the inertia of the state, for example in translating policy into practice, and oppose discriminatory laws that stigmatize and marginalize people living with HIV. An example of this is the Treatment Action Campaign in South Africa, which has developed a cadre of spokespersons who are HIV-literate, articulate, and confident. Two key organizations in Mexico, that also are participants and partners in the Mo Kexteya project, have worked hard to combat stigma: one (FRENPAVIH) through advocacy and political pressure; the other (the Mexican Network of People Living with HIV/AIDS) through development of training and support tools and systems. Finally, lessening internal stigma strengthens the ties between people living with HIV and their families and communities, thereby promoting *social capital* and community coherence.

ADDRESSING INTERNAL STIGMA

Given that internal and external stigma are intrinsically linked—because experiences with external stigma often exacerbate internal stigma and positive experiences with others can reduce internal stigma and increase self acceptance—it is crucial that comprehensive interventions address both dimensions of HIV-related stigma. Internal stigma cannot properly be addressed in the absence of interventions to address external stigma. At the very least, directly addressing external stigma should indirectly have an impact on internal stigma as well.

Since stigma is socially constructed, it is critical that a holistic approach is taken in addressing it: stigma should be addressed at the level of laws and government policies, at the level of institutions such as health and education systems, in media campaigns and by media practitioners, at the level of community and family interactions (including faith-based and cultural organizations), and in workplaces.

At all of these levels, a very effective methodology for addressing internal stigma is to conduct workshops that promote self awareness and provide for growth through experiential learning, values clarification, and attitude change. As with behavior change related to HIV risk, none of these approaches are simple or

straightforward, and stigma mitigation is seldom thought through at all these levels. Another key aspect of addressing stigma is the provision of good healthcare, particularly ARVs for those who need them. These interventions may lessen some of the fear associated with HIV and AIDS and diminish the need for distancing and othering. And, of course, addressing poverty and all forms of inequality improves the life circumstances of a country's citizens, thereby reducing the likelihood of stigma, stress, or resentment linked to the drain on family and community resources that can accompany coping with HIV.

At the Social Level

- **Promoting positive role models.** Disclosure of HIV status by prominent members of society can play an important role in promoting visibility of HIV-positive people and breaking down some of the silence and fear surrounding HIV. People living with HIV who are leading productive lives and are successful and confident can be an inspiration to others affected by the epidemic. Leadership also should be encouraged from opinion leaders across sectors—for example, businessmen, artists, musicians, sports personalities, celebrities, and politicians who, through their leadership and creativity, can mitigate stigma associated with HIV.

Guidelines for Addressing Stigma

Both the Siyam'kela and Mo Kexteya projects developed guideline documents to shape good practice in stigma mitigation. These are available at:

<http://www.policyproject.com/siyamkela.cfm>

<http://www.policyproject.com/MoKexteya.cfm>

- **Working with cultural institutions.** Cultural organizations, initiation schools, traditional leaders and healers, community leaders, and others all play a role in shaping attitudes and values regarding HIV, gender, sexual orientation, and those who are in any way seen as different. It is vital to use interventions that assist community-based role players in clarifying their values, debunking myths, acquiring new information, and actively supporting the development of a positive self image in people living with HIV. Communities whose resources are stretched need support for ARVs and vaccine initiatives and should be assisted to minimize the negative impact of HIV on development.
- **Addressing health service delivery.** Healthcare workers need assistance in clarifying their values and attitudes so that they can create safe and stigma-free spaces in healthcare settings. A study conducted by the Centre for the Study of AIDS found much suspicion and antipathy among community members about health workers. Many people living with HIV recounted stories of ill treatment of themselves or others by nurses. Most were able to recount stories of being forced to wait to go to the bathroom or being told to “go yourself”; staff disclosing HIV status of clients and gossiping about patients in front of others; and staff passing “funny remarks,” refusing treatment, giving the wrong medication, or placing HIV-positive patients in specific wards (Centre for the Study of AIDS, 2004). In a survey of health service providers, the Mo Kexteya project found various forms of

stigma and discrimination in all sectors of health service delivery. Breaches of confidentiality, negative attitudes, differential treatment, unrealistic fears of infection, and unnecessary levels of isolation were among the common examples of stigmatizing behavior found in service delivery centers, including hospitals. In part, health worker attitudes may be driven by genuine and reasonable fears of infection which could be addressed by providing information about and supplies to use universal precautions. In addition to working directly with healthcare workers, system-wide approaches—with interventions at every level (e.g., from management to administration, and revision and development of protocols and procedures)—are needed to support an overall, non-stigmatizing healthcare setting.

- **Addressing the faith sector.** The Siyam’kela Project suggested that faith organizations develop good policies, train leaders on HIV and stigma, build strategic community partnerships, and develop interventions to mitigate stigma. These include involving people living with HIV (including HIV-positive clergy) in faith programs, thereby promoting a sense of worth in those congregants who are HIV-positive; and developing prevention messages that do not stigmatize. For example, messages that emphasize abstinence and faithfulness—while within the domain of faith organizations and considered important strategies for preventing HIV— inadvertently may stigmatize or marginalize those who are HIV-positive. While abstinence and faithfulness messages remain valid,

it is important to deliver them in ways that do not stigmatize and marginalize people living with HIV. This can be achieved by working with people living with HIV on message delivery, as well as by having open and frank discussions relating to this issue. One South African church minister, the Reverend Martin Nobula, specifically challenged internal stigma by emphasizing biblical messages of love and acceptance, “In the midst of the challenges of HIV/AIDS, we can be assured that God still loves us ... God promises to bring good results out of difficult situations ... HIV affects the body but hope is found in the soul” (POLICY Project et al., 2004, p. 12).

At the Contextual Level

- **Strengthening self-support groups for people living with HIV.** Support groups, that are facilitated by HIV-positive people themselves, send a clear message of competence and independence to group members and their communities. One of the consequences of internal stigma is a withdrawal from social and health services, so these support groups can provide a safe space for support, exploration, and growth and, in turn, people living with HIV can achieve the confidence to assert their rights in various settings.
- **Fostering support groups.** The majority of people living with HIV who were interviewed in the Siyam’kela Project emphasized how valuable and important counseling, information, and support groups (both formal and informal) had been in their journey to overcoming the emotional upheaval of discovering their positive status, as

well as in starting to live positively. Many stories were shared about how people had not received any pre- or post-test counseling for their HIV test. As a result they had been uninformed about the virus and relied on popular knowledge and myths, and on ill-equipped medical practitioners for guidance. Countless HIV-positive people were informed, upon receiving their results, that they would die within a couple of days. Only a handful could share positive experiences of proper counseling. Many people living with HIV believed that it would be very useful for people who are themselves living with HIV to provide pre- and post-test counseling. Support groups for those experiencing “courtesy” stigma also are important interventions to assist those close to people living with HIV in processing the internal stigma they may be experiencing.

- **Building family support.** Families need assistance to process their thoughts and feelings about their HIV-positive family members. This may include family counseling and support group work. It also should involve information-giving, demystifying beliefs, clarifying values, and accessing resources to lessen the burden on the family.
- **Addressing stigma in the workplace.** The Siyam’kela Project recognized the important role of government workplaces in providing real leadership on stigma mitigation to other workplaces and to society at large. One significant intervention which was shown to have had a profound impact on government workplaces was the GIPA Project, a project designed on

the principle of the Greater Involvement of People Living with HIV/AIDS. People who were openly living with HIV were recruited to work as HIV coordinators in different government departments. The coordinator from the Interdepartmental Committee on HIV/AIDS noted, “It sends a strong message of acceptance to other employees. They get to see this strong person who is HIV-positive. It also gives the opportunity for informal counseling in the workplace of the person living with HIV who is openly talking to other employees. And then also, it normalizes HIV/AIDS ... and I suspect it creates a momentum, which makes it easier for other people living with HIV to disclose and this reduces stigma and discrimination” (POLICY Project et al., 2004, p. 18).

In Mexico, Mo Kexteya partners and other groups have facilitated the formation of the National Business Coalition on HIV/AIDS. The coalition, which was officially launched in early 2005, encompasses more than 20 multinational and national corporations in Mexico that came together to reduce HIV-related stigma and discrimination in the workplace.

At the Self Level

- **Building self-esteem.** Counseling and support groups help with personal growth, self-esteem, and self worth. Support groups facilitate a sharing of experiences, convey information, and give practical advice on a range of HIV wellness and treatment options. They assist with social confidence, improve individuals’ social capital by

helping them to be a part of organizations, feel a sense of connection to their community, believe that they can influence social processes, and develop a sense of trust in social institutions and authorities.

- **Developing economic independence.** Economic independence can engender a sense of self worth in a person living with HIV. Reduced reliance on partners and families can reduce the economic burden that may have come from caring for someone living with HIV or AIDS. This, in turn, can diminish potential hostility toward the person living with HIV, positively affect stigma, and thus reduce internal stigma. The provision of ARVs is a critical aspect of this: treatment promotes wellness and an ability to work and contribute to household income. On a broader level, increased economic stability among the general population of a country will have an impact on diminishing HIV-related stigma.
- **Building leadership skills.** People living with HIV who are given opportunities for self development can learn to overcome internal stigma. Many community-based organizations train their members in leadership skills so that they can get involved in community development. The Siyam’kela Project, for example, has provided master training to 18 HIV-positive peer educators working for DramAidE. These peer educators are based at institutions of higher learning in provinces across South Africa. The master training has built their capacity to boldly mitigate HIV-related stigma in their environments. Their visibility and confidence is inspiring, and these skills are transferable to other settings.

- **Empowering people living with HIV who interact with the media.** The Siyam’kela Project noted the power of media to shape perceptions and attitudes towards HIV and so has developed empowerment workshops for people living with HIV to improve their skills in working with media practitioners. All of the people living with HIV who had developed confidence in working with the media showed similar traits: they had dealt with disclosure issues well before working with the media; they had confronted their own internal stigma; they prepared well for media interviews; they established a strong personal support base; they knew in advance what kind of message they wished to convey; they challenged the media practitioner on stigma; they encouraged practitioners to move beyond simplistic stories to more complex ones; they asserted their right to see stories prior to publication; they actively sought to develop skills in working with media; and they shared their skills and successes with other people living with HIV (POLICY Project et al., 2004). As part of Mo Kexteya, partners produced a photojournal profiling 10 people living with HIV to help counteract stereotypes and provide the media with positive images of those affected by the epidemic (Letra S et al., 2004).
- **Counseling.** Many people living with HIV need to be assisted to process internal stigma through individual counseling and in support groups so that they can be good role models for others and be able to stand up to stigma when they experience it. Unpublished

research conducted at a large South African hospital found, for example, that disclosure was a process in which individuals first had to come to terms with their new status and understand fully its implications so as to be in a position to tell others about it. While the study found that many of the participants seemed to be getting support at the household level, this was often limited and conditional and often was dependent on the assertiveness, confidence, and positive role modeling from the person living with HIV. This behavior often required extensive support from counselors (Skhosana, 2004).

- **Facilitating internal stigma workshops.** Siyam’kela has developed a one-day workshop aimed at HIV-positive people that focuses specifically on internal stigma. Themes covered in this workshop include definitions of stigma, personal experiences of stigma, rating one’s own internal stigma, strategies to challenge internal stigma, media interaction skills, personal effectiveness, and stigma advocacy.
- **Mainstreaming internal stigma in all HIV workshops.** The Siyam’kela Project has embarked on a training process for a group of 20 people living with HIV from across South Africa who work as health promoters in tertiary institutions. This training aims to empower the participants to conduct advocacy workshops on HIV-related stigma, to address their own internal stigma, and to work more effectively with media and faith-based organizations and communities.

CONCLUSION

Internal stigma is a complex and subtle phenomenon, affecting many people living with HIV around the world. It is influenced by external stigma and a combination of social, community, and self factors, some of which may be intrinsic to an individual person living with HIV. Addressing internal stigma needs to happen at multiple levels: individual, contextual, and societal. If we fail to address stigma, we limit the potential of people living with HIV to live full and productive lives and assert the rights to which they are entitled, and we hinder all prevention, treatment, and care efforts.

An important starting point for developing evidence-based stigma reduction interventions is to design indicators that are capable of measuring stigma and discrimination, as well as the impact of different program approaches. UNAIDS currently is working with people living with HIV, international donors, NGOs, human rights experts, and others to develop a global set of indicators that can be used to inform and monitor stigma and discrimination mitigation efforts. POLICY and other members of USAID’s Stigma and Discrimination Indicators Working Group are contributing to this global effort.

Table 2 presents an expanded set of internal stigma indicators developed by the Siyam’kela and Mo Kexteya projects for measuring and assessing different facets of internal stigma, such as self exclusion and perception of self (POLICY Project et al., 2003b; National Institute of Public Health et al., 2004). These themes and indicators can help program planners and policymakers think about the types of internal stigma they need to address,

TABLE 2. INDICATORS OF INTERNAL STIGMA

THEME	INDICATOR
Self Exclusion	<ul style="list-style-type: none"> ▪ Number of people living with HIV who choose not to access existing support services ▪ Number of people living with HIV who state that they have avoided seeking health services because of shame related to their HIV status ▪ Number of people living with HIV who have avoided services due to fear of discrimination ▪ Number of people living with HIV who choose not to apply for a job because of their fear of being exposed as HIV-positive
Perception of Self	<ul style="list-style-type: none"> ▪ Number of people living with HIV who have low self-esteem as a result of their HIV-positive status ▪ Number of people living with HIV who state that HIV is a result of their sexual orientation ▪ Number of people living with HIV who state having had suicidal tendencies or thoughts because of their HIV status ▪ Number of people living with HIV who state having felt HIV-related guilt linked to religious precepts ▪ Number of people living with HIV who state having felt shame linked to their HIV-positive status ▪ Number of people living with HIV who state having felt dirty or “dangerous” because of their HIV-positive status
Social Withdrawal	<ul style="list-style-type: none"> ▪ Number of people living with HIV who have fewer interactions with people than before they learned their HIV status ▪ Number of people living with HIV who isolate themselves because of HIV ▪ Number of people living with HIV who choose not to have intimate relationships ▪ Number of people living with HIV who state that they stopped having sex because of acquiring HIV ▪ Number of people living with HIV who have fewer interactions with HIV-negative people ▪ Number of people living with HIV who changed their place of residence because they were afraid of the reactions of their families or community
Overcompensation	<ul style="list-style-type: none"> ▪ Number of self reports from people living with HIV who believe they contribute more than people who are not living with HIV as a means of proving themselves
Fear of Disclosure	<ul style="list-style-type: none"> ▪ Number of people living with HIV who have disclosed their status ▪ Number of people living with HIV who are willing to publicly disclose their status to the media ▪ Number of people living with HIV who would not disclose their HIV-positive status due to fear of stigmatization ▪ Number of people living with HIV who report positive reactions to their disclosure ▪ Number of people living with HIV who report having been forced or coerced to disclose to their partner
Subterfuge	<ul style="list-style-type: none"> ▪ Number of people living with HIV who state that they have lied about their HIV-positive status to their family or friends for fear of the withdrawal of others ▪ Number of people living with HIV who state that they have hidden their status while seeking employment or in their workplace ▪ Number of people living with HIV who state that they have stopped taking ARVs because they felt fear about being questioned about their health ▪ Number of people living with HIV who state that they have lied about their HIV-positive status to their sexual or intimate partners

Note: All of the above indicators can be further disaggregated by sex, age, sexual orientation, race, and geographical location.

as well as provide a tool for determining the current level of internal stigma and the impact of interventions on internal stigma over time.

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