

**POLICY Project**

**CORE PACKAGE FINAL REPORT:**

**Siyam'kela: Measuring HIV/AIDS  
Stigma in South Africa, 2002–2004**

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**April 2004**



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## **Abstract**

In 2002, the POLICY Project embarked on an HIV/AIDS stigma research project in a country that has a substantial HIV/AIDS epidemic.

The POLICY Project developed HIV/AIDS indicators and guidelines for stigma mitigation through a participatory, consultative process. The project carried out a qualitative research study in three sectors that play a leadership role in South Africa: the faith-based sector, national government departments, and the media. The research was conducted in communities across South Africa, and of the focus group participants, 85 percent were black, 55 percent were women, and 43 percent were people living with HIV/AIDS.

HIV/AIDS indicators were developed to assist HIV/AIDS program managers to monitor and evaluate the effectiveness of their stigma mitigation efforts. Comprehensive guidelines were also developed to guide and strengthen HIV/AIDS programs to ensure that HIV/AIDS stigma mitigation programs are mainstreamed, resulting in a comprehensive and effective response to the HIV/AIDS epidemic in South Africa.

Further funding has been secured through USAID/South Africa to continue the project and ensure that the findings, tools, and documents from this research will be used, tested, and improved and that they inform training interventions in the next phase of the project.



## Abbreviations

AIDS	Acquired immune deficiency virus
ARV	Antiretroviral
CADRE	Centre for AIDS Development, Research, and Evaluation
CSA	Centre for the Study of AIDS
DPSA	Department of Public Service and Administration
FOHAP	Faith Organizations in HIV/AIDS Partnership
GIPA	Greater involvement of people living with HIV/AIDS
HBC	Home-based care
HCBC	Home/community-based care
HIV	Human immunodeficiency virus
HSRC	Human Sciences Research Council
MSF	Médecins sans Frontières (Doctors without Borders)
NAPWA	National Association of People Living with HIV/AIDS
NEHAWU	National Education, Health, and Allied Workers' Union
PLHA	Person Living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission
SOHACO	SOWETO HIV/AIDS Counsellors Association
STI	Sexually transmitted infection
TB	Tuberculosis
VCT	Voluntary counseling and testing



## **Introduction**

In addressing the United Nations General Assembly in 1987, the late Jonathan Mann, the founding director of the United Nations Global Program on AIDS (UNAIDS), described what he saw as the three phases of the HIV/AIDS pandemic (Parker and Aggleton, 2002a):

- The first phase of HIV infection, often unnoticed and silent
- The second phase of the AIDS epidemic, with a range of infectious diseases and the disease becoming more visible
- The third phase, potentially the most damaging of all, with an epidemic of social, cultural, and political responses to AIDS, including stigma, discrimination and denial

In South Africa, a country where HIV/AIDS pandemic significantly affected society, these words are particularly relevant and prophetic. There has been a significant social, cultural, and political response to the HIV/AIDS epidemic and this has included stigma, discrimination, and denial at all levels of society.

The 2002 antenatal survey, conducted by the National Department of Health, showed that 26.5 percent of pregnant women were HIV positive. Another study, undertaken in November 2002 by the Human Sciences Research Council (Shisana and Simbayi, 2002), based on HIV tests conducted on a representative group of 8,840 people, predicted that 11.4 percent of citizens over the age of two were HIV positive. Such a high prevalence rate highlights the profound effect HIV/AIDS has on all South Africans. High levels of stigma, discrimination, and denial are, therefore, extremely harmful to effectively managing the epidemic.

In September 2001, Peter Piot, UNAIDS executive director, said that “HIV-related stigma and discrimination remain an immense barrier to effectively fighting the most devastating epidemic humanity has ever known. If HIV-related stigma and discrimination are not tackled, AIDS will blighten the 21st century just as racism affected the 20th century” (UNAIDS, 2001).

To highlight and focus efforts on creating a better understanding of HIV/AIDS-related stigma and discrimination, World AIDS Day focused on stigma and discrimination as its theme for 2002. In response, POLICY recognized that it was important to conduct research into HIV/AIDS stigma that would provide information to assist program planners and managers in addressing the issue. Specifically, the research aimed to develop indicators of stigma that would provide tools to monitor and evaluate the effectiveness of HIV/AIDS stigma-mitigation efforts.

The research project, locally named Siyam’kela,<sup>1</sup> developed indicators of HIV/AIDS stigma to measure internal and external stigma. In addition, POLICY contributed to understanding HIV/AIDS stigma in South Africa through the collection of information on the topic. As a result of this project, the following Siyam’kela reports are available:

- Measuring HIV/AIDS Stigma: A Literature Review
- Examining HIV/AIDS Stigma in Selected South African Media: January–March 2003
- HIV/AIDS Stigma Indicators: A Tool for Measuring the Progress of HIV/AIDS Stigma Mitigation
- Tackling HIV/AIDS Stigma: Guidelines for the Workplace
- Tackling HIV/AIDS Stigma: Guidelines for People Living with HIV/AIDS Who Interact with the Media
- Tackling HIV/AIDS Stigma: Guidelines for Faith-Based Organizations
- Promising Practices of Stigma Mitigation Efforts from Across South Africa: Reflections from Faith-Based Organizations, People Living with HIV/AIDS Who Interact with the Media, and HIV/AIDS Managers in the Workplace

The development of indicators of HIV/AIDS stigma has been significant, as few efforts have been made to date to develop monitoring and evaluation tools that we know measure HIV/AIDS stigma. In addition, the documentation of guidelines and promising practices helps HIV/AIDS program managers to understand stigma and respond appropriately to recognize it and mitigate its impact.

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<sup>1</sup> Siyam’kela is an African word from the Nguni language. Translated it means “We are accepting,” expressing a collective embracing, understanding, and acceptance of a challenge at a particular time. The word has thus been interpreted as “Together We Stand” for this project. The project has been designed to explore HIV-related stigma, an aspect of the HIV/AIDS epidemic, which is having a profoundly negative effect on the response to people living with and/or affected by HIV/AIDS. Within the context of this project, Siyam’kela denotes a collective approach in working toward reducing HIV/AIDS-related stigma and discrimination.



## Analytical Framework

The concept of stigma is often used interchangeably with that of discrimination (Population Council, 1999; Advocacy for Action on Stigma and AIDS in Africa, 2001). However, their meanings differ. It is important to understand the different meanings of the terms to effectively target stigma and discrimination.

**Discrimination** focuses on behavior (Manser and Thomson, 1999) and is “the unjustifiably different treatment given to different people or groups.”

In contrast, **stigma** is defined as an attribute or quality that (UNAIDS, 2002a) “significantly discredits” an individual in the eyes of others. Importantly, stigma is a process. Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy. The stigmatized person is seen to possess a spoiled or polluted identity that is considered different or deviant to societal norms and that deserves sanctioning (Erving Goffman, in Parker and Aggleton, 2002a). Stigma is thus an attribute used to set affected persons aside from the normalized social order, and the separation involves an implicit devaluation (Population Council, 1999).

Parker and Aggleton (2002a) suggest that the dominant definition of stigma as an “undesirable difference” ignores the fact that stigma is socially constructed. They oppose the idea that stigma is a static individual characteristic and argue in favor of stigma as a social process. Ultimately, stigma creates and is reinforced by social inequality (UNAIDS, 2000b).

Stigma has been identified as a complex, diverse, and deeply rooted phenomenon that is dynamic in different cultural settings. As a collective social process rather than a mere reflection of an individual’s subjective behavior, it operates by producing and reproducing social structures of power, hierarchy, class, and exclusion and by transforming difference (class, race, ethnicity, health status, sexual orientation, and gender) into inequality (ICRW, 2002; Population Council, 2002; UNAIDS, 2002b). As Herek and Glunt note (in Population Council, 1999, p. 2), “... the stigma attached to AIDS as an illness is layered upon pre-existing stigma.”

Bollinger (2002) concurs that there are a number of reasons why stigma affects those with HIV/AIDS:

- HIV/AIDS is ultimately fatal, and this causes fear of infection
- HIV/AIDS is often associated with behavior that is already stigmatized (e.g., sex work, drug taking)
- Becoming infected is seen as the result of choices made by the individual
- Having HIV/AIDS is also seen as a punishment for deviant behavior

Stigma can be characterized as *internal* or *external* (UNAIDS, 2002b). **Internal stigma** (felt or imagined stigma), which is experienced by people living with HIV/AIDS (PLHAs), is the shame associated with HIV/AIDS and the fear of being discriminated against.

Internal stigma may have different effects. Internal stigma often causes refusal or reluctance to disclose HIV status or denial of HIV/AIDS. For example, felt stigma may lead HIV-positive nursing mothers who are aware of their positive status to breastfeed (despite the dangers of transmission to the child) because of fear of the revelation of their status arising from bottle feeding. Internal stigma may be chosen as a survival mechanism to protect oneself from enacted stigma (Brown, Macintyre, and Trujillo, 2002).

**External or enacted stigma** refers to actual experiences of discrimination (UNAIDS, 2000a). This may include the experiencing of domination, oppression, the exercise of power or control, harassment, categorizing, accusation, punishment, blame, devaluing, prejudice, silence, denial, ignorance, anger, a sense of inferiority, social inequality, exclusion, ridicule, resentment, or confusion. It may sometimes lead to violence against a PLHA (Parker and Aggleton, 2002a; UNAIDS, 2002b). Marshall (in Parker and Aggleton, 2002b) describes enacted stigma and discrimination as a collective dislike of what is unlike. Enacted stigma is usually intentional, although people are not always aware that their attitudes and actions are stigmatizing (ICRW, 2002).

It has been suggested that stigma is applied with varying degrees of force, depending on local moral judgments about how a PLHA contracted HIV (Population Council, 1999). For example, in Southeast Asia, the AIDS discourse comprises a clear continuum of “guilt” and “innocence,” with sex workers or injection drug users seen as most guilty, followed by clients of sex workers. Monogamous wives infected by their partners are seen as most innocent, followed by HIV-positive children infected during pregnancy, childbirth, or breastfeeding. In South Africa, it appears that women who are infected are stigmatized more than infected men (Department of Health, 2002a).

An unfortunate aspect of stigma is its overwhelmingly powerful capacity to produce internalization and acceptance of inferiority by the oppressed group and justification of discrimination by the dominant group. Therefore, its primary effects are to (Population Council, 2002):

- Create ‘difference’ between groups of people and social hierarchy
- Produce, legitimize, and perpetuate social inequality

With this in mind, the project was guided by the conceptual framework of Aggleton and Parker in UNAIDS (2002a), which recognizes that “HIV/AIDS stigma often leads to HIV/AIDS discrimination. This in turn, leads to the violation of human rights of people living with HIV/AIDS, of their families, and even those presumed to be infected, such as family members or other associates.”

Specifically, the project focused on stigma—particularly internal stigma—as a key part to the conceptual framework, as it was felt that stigma was less understood. Discrimination, as an act, is much easier to identify, document, and have recommendations for recourse; however, stigma is more subtle and therefore harder to address and change. The process of developing HIV/AIDS stigma indicators and guidelines to mitigate stigma are described further in this paper, with Section III describing the context: South Africa in relation to HIV/AIDS and the response to the epidemic. This section also broadly describes some responses to HIV/AIDS from faith-based organizations, government, and the media. These are the focus areas in which the research was conducted. Section IV

highlights the challenge that this project tried to address, as well as the strategy used by the POLICY Project in conducting the full research project that led to the development of indicators and guidelines. Section V then describes the findings and suggests key indicators that can be used by program managers to monitor and evaluate stigma-mitigation efforts. Furthermore, this section highlights stigma mitigation guidelines for faith leaders, managers in the workplace, and PLHAs who interact with the media. Section VI provides the summary and Section VII discusses POLICY's impact and the implications for South Africa in the future.



## **Addressing Stigma and Discrimination in the South African Context: 2002–2004**

### **The Size of the HIV Epidemic**

It is difficult to estimate the precise national HIV prevalence in South Africa. However, in November 2002, based on HIV tests conducted on a representative group of 8,840 people, the Human Sciences Research Council (Shisana and Simbayi, 2002) predicted that 11.4 percent of citizens over the age of two were HIV positive.

The 2002 antenatal survey, conducted by the Department of Health (2003), shows that 26.5 percent of pregnant women were HIV positive in 2002. Prevalence among pregnant women under age 20 has dropped (from 15.4% to 14.8%), which may indicate that safer sex messages aimed at youth are starting to work. However, a worrying trend was the increase among older women, particularly the dramatic jump from 9.8 percent to 17.2 percent among those over the age of 40.

### **The Shape of the Response**

The HIV/AIDS epidemic in South Africa is extremely dynamic, and, during the period when the research was undertaken, several key strategies were embarked upon as part of a comprehensive response to the epidemic.

The *Strategic Plan for HIV/AIDS and STDs 2000–2005* provides the framework for the HIV/AIDS response. The plan rests on four pillars: prevention; treatment and care; human and legal rights; and monitoring, research, and surveillance. The strategic plan corresponds broadly with the objectives in both the Abuja Declaration on HIV/AIDS and other related infectious diseases (April 2001) and the UNGASS Declaration of Commitment on HIV/AIDS (June 2001). South Africa is a signatory to both these declarations.

*Prevention.* Prevention efforts focus on condom distribution and education programs aimed at changing sexual behavior, promoted largely through life skills programs and public awareness campaigns run primarily by the Khomanani, LoveLife, and Soul City projects. While it is hard to evaluate behavioral change, there is evidence from Department of Health and Human Sciences Research Council (HSRC) research studies that more people, particularly youth, are using condoms and abstaining from sex (Shisana and Simbayi, 2002). Approximately 350 million free condoms were distributed in 2002–2003 by the Department of Health. However, a recent survey of clinics revealed that only 37 percent of clinics had instructions on how to use the condoms (Department of Health, 2004).

*Treatment, care, and support.* While Department of Health guidelines on the treatment of opportunistic infections exist, it is generally agreed that the department faces many challenges in the delivery of health services in general and certainly in the identification of HIV-positive clients, in the treatment of opportunistic infections, and in the main

prevention program, which seeks to prevent HIV transmission from infected mother to child. For example,

- In 2001, the tuberculosis (TB) cure rate was only 54 percent—with the target being set at 85 percent.
- A recent survey of 962 public clinics found that there was generally poor uptake of HIV counseling and testing. On average, only 20 people a month were tested at facilities offering HIV testing. Most tests were done in KwaZulu-Natal and the Western Cape, and most tended to be on pregnant women (Department of Health, 2004).
- There has also been mixed response to the prevention of mother-to-child HIV transmission (PMTCT) program. In the northwest, for example, the uptake rate of HIV testing among antenatal clinics was only 14 percent at two pilot sites (Thom, 2003). The quality of counseling is crucial to the success of the program, and more effort needs to be put into ensuring community support for the program, which can now be linked to provision of antiretrovirals (ARVs) for HIV-positive mothers.

On the positive side, more than 400 home-based care (HBC) organizations are supported by the Department of Health, and the department has appointed HBC coordinators in all provinces. While the quality of care is likely to vary between these organizations, and the care of AIDS orphans remains an issue that needs priority attention, the Department of Health has hosted a significant number of national home/community-based care conferences that outlined key recommendations in relation to the care and support of PLHAs (Department of Health, 2002s).

*Human and legal rights.* While South Africa has a constitution that makes it illegal to discriminate against people with HIV/AIDS, stigma and discrimination continue to flourish. In Khayelitsha, ARVs have been available at certain clinics for the past three years as part of a project coordinated by Médecins sans Frontières (MSF). According to the MSF, this has assisted in breaking down stigma as more and more people have come forward to declare their HIV status. On November 19, 2003, the South African Cabinet made an important announcement: that it would provide ARV drugs in the public health sector. The announcement removed much of the antagonism that had built up between government and civil society organizations over the issue of ARV treatment over the last few years. The treatment program will not only provide comprehensive care and treatment for PLHAs, but the substantial resource infusion also brings a rare opportunity to strengthen the country's entire healthcare system. The national rollout offers many more such opportunities, provided that it is linked to significant public awareness and community mobilization to encourage people to check their HIV status and enroll for treatment.

*Monitoring, research, and surveillance.* In an exciting research development in 2003, Phase 1 of an HIV vaccine developed by a team of South African and U.S. scientists was launched in Johannesburg and Durban. In addition, the Medical University of South Africa is monitoring adverse reactions relating to ARVs. Government monitoring and surveillance of the epidemic continues, assisted by a range of organizations such as the Medical Research Council and the HSRC.

From the description above, it is clear that South Africa has a comprehensive approach to the HIV/AIDS epidemic; however, stigma and discrimination continue to flourish. Stigma and discrimination remain a real issue in the South African context. Stigma affects all aspects of the plan outlined above and whether prevention efforts will be effective. The poor uptake of voluntary counseling and testing (VCT) and PMTCT are surely some indicators of stigma. In relation to care, the negative attitudes of healthcare workers toward PLHAs remain a problem (ICW, 2004) and diminishes the uptake of VCT, PMTCT, ARVs, and home/community-based care (HCBC).

As part of the research, we conducted a media scan at the time that the field work was conducted (January–March 2003). It is useful to consider the study conclusions, as they provide an understanding of the general messages being conveyed to the general population regarding HIV/AIDS. “Othering,” or the practice of situating oneself outside of risk for HIV, still seems to be widely used in South Africa. Black and poor people tend to be blamed for the HIV/AIDS epidemic, leaving a general sense of immunity for white, middle class, and wealthy people. In all three types of media scanned, the perception seemed to be reinforced that HIV/AIDS is a disease affecting mostly black women (POLICY Project, 2003).

The research collected information about three sectors: the faith-based sector, the media, and in the government (as an example of a workplace). It is important to understand these sectors in more depth in order to look at their response to HIV/AIDS in relation to stigma.

Faith-based organizations often associate HIV/AIDS with allegations of sexual immorality, and this may lead to severe negative sanctions. In many countries—both developed and developing—this is due to the perception that HIV/AIDS is a punishment from God (UNAIDS, 2002a; Population Council, 2002). Faith organizations, including churches, have a key role to play in discouraging and challenging this perception. Many reports in Africa describe PLHAs receiving discriminatory treatment, including ostracism, from faith organizations because of their status. This has sometimes resulted in PLHAs being summoned for special prayers or confessional sessions before congregations, often based on fraudulent and insistent claims about miracle cures for HIV/AIDS (UNAIDS, 2002a). Exaggerated fears of contagion have led to PLHAs being ordered to be last when taking Holy Communion in churches or being excluded from religious rites altogether (Campbell and Rader, 2002).

However, there is also evidence that religious leaders can be sensitive to the needs of PLHAs and can play a major role in promoting a culture of acceptance and respect for PLHAs, including notions of responsibility and tolerance (Vitulo, 2002). Provision of spiritual and moral care to those infected and affected by HIV/AIDS is necessary because PLHAs may experience a range of emotions arising from stigma, including fear of death, depression, suicidal thoughts, guilt, anguish, anger, denial, shock, rejection, and isolation (Population Council, 2002).

Some researchers suggest that religious leaders can also play a vital role in educating people about the prevention of HIV transmission, over and above the current discourse of abstinence and being faithful to one partner. The ideal for religious leaders is usually the

promotion of “sound family values” and no sex out of marriage, but the reality for many people is very different (Faith in Action, 2002). Religious leaders need to base their teachings on the reality of people’s lives, and not just on abstract ideals. Some religious leadership—such as the Anglican hierarchy in Kenya and the Catholic leadership in the United States—has taken a strong stand in declaring stigma and discrimination sinful and unacceptable (Council of Anglican Provinces in Africa, 2002; Vitillo, 2002). To be effective, this message needs to filter down to congregations and clergy at local levels.

Stigma in many countries is expressed through laws and policies directed at PLHAs that claim to protect “the general population” (Population Council, 2002). Such examples of stigmatization include compulsory screening and testing for HIV, compulsory notification of AIDS cases, prohibition of PLHAs from certain occupations, and isolation of PLHAs from uninfected segments of the population. South Africa has more enlightened laws prohibiting discrimination, but actual practice falls far behind the progressive principles enshrined in legislation (Department of Health, 2002a).

Another widespread example of stigma concerns limitations on international travel and migration. Despite widespread agreement among governments that laws restricting freedom of movement for PLHAs are discriminatory, many countries have adopted policies that restrict travel and free movement between countries. Foreigners have been deported from a wide range of developed and developing countries after authorities have discovered their HIV-positive status (Population Council, 2002a).

Finally, a problem more specific to South Africa has been conflicting messages emanating from the government concerning HIV/AIDS, together with bad judgment calls regarding policy. This has had the effect of nullifying the work done by AIDS activists to demystify the disease and increasing stigma (Department of Health, 2002a; Bollinger, 2002).

The language used to describe HIV/AIDS plays an important role in shaping perceptions (Soul City, n.d.). Words such as “victim,” “AIDS carrier,” and “sufferer” stigmatize PLHAs and create images of powerlessness. Prejudices are perpetuated by media portrayal of HIV-positive people as helpless and hopeless. PLHAs are commonly portrayed in the visual media as emaciated, passive, and dying; there is little coverage of people who are living positively with HIV.

Media reporting of HIV/AIDS has also used the language of guilt versus innocence and the metaphor of war, often depicting AIDS as a disease of the “other” (Richter, 2001). Often HIV/AIDS has been branded a disease of only particular groups: in the early days of the pandemic these were gay men, Haitians, and sex workers; more recently, it has been Africans and people of color. HIV/AIDS has also been seen as reflecting irresponsibility or sinfulness. These modes of depiction usually create a false sense of protection as they permit the disease to be seen as characteristic of the “other.”

The sheer volume of media reporting in South Africa on HIV/AIDS has increased with time but has been dominated by sensationalism (CADRE, 2002). Reporting has focused on wild speculation about the origins of the virus, the political conflict between role-players in the HIV/AIDS arena, the inadequacy of government strategies, and the sheer

devastation caused by the disease. It has been claimed that these issues appeal to the media audience. However, misleading and false information has produced fear and confusion.

Many journalists find HIV/AIDS difficult to confront because of the relationship between HIV infection and social and political inequalities in South Africa. The effects of HIV/AIDS on poor and vulnerable communities are more visible, and journalists find it challenging to report on HIV/AIDS and still avoid stigmatizing such communities (CADRE, 2002). Some editors are also said to have exercised their editorial role in a manner that has trivialized or misrepresented the pandemic.

Reorientation of media professionals to use non-alarming, non-discriminatory and non-moralistic language in HIV/AIDS reporting will enable the media to be used to promote hope and acceptance, and to reduce stigmatization (CADRE, 2002; UNAIDS, 2002a). Partnership with PLHAs in HIV/AIDS journalism can create solidarity and hope and can be achieved by the training of journalists and reviewing of editorial policy on the quality of HIV/AIDS reporting (CADRE, 2002).

The HIV/AIDS pandemic has elicited both negative and positive responses from families and communities. Following disclosure of HIV-positive status, some families and employers have come together, offered sympathy and care, and sometimes contributed funds toward monthly purchases of ARV drugs (Brown, MacIntyre, and Trujillo, 2002). Disclosure has also evoked stigma and discrimination. Such a response inhibits disclosure by other people and undermines strategies aimed at the prevention of HIV transmission and the promotion of VCT (UNAIDS, 2001).

In the majority of developing countries, the family is often the only source of caregiving for HIV-positive individuals (UNAIDS, 2002a); hence, it is important to reduce stigma in this sphere. Yet stigma within the family has also been described as the most subtle and insidious form of stigma and the hardest to effectively address (Advocacy for Action on Stigma and HIV/AIDS in Africa, 2001). By inhibiting open communication in the family, stigma makes disclosure difficult. Without disclosure, prevention and care are nearly impossible.

Social exclusion of PLHAs, beginning in the family and extending into the community, has also been linked to poor self-esteem. PLHAs with poor self-esteem are more likely to engage in high-risk sexual behavior, thus perpetuating the spread of the virus (Terence Higgins Trust, n.d.).

The impact of stigma is mediated by gender, and its impact is experienced more by women than by men. This is rooted in the current social constructions of sexuality and sexual relations, which accept male promiscuity and blame women for the spread of HIV (UNAIDS, 2002b). There is extensive evidence that females and non-heterosexual male PLHAs are more likely to be badly treated than children and heterosexual men. Evidence from around the world shows that attacks on men who are assumed to be gay have increased, and that sex workers (often blamed for HIV transmission) have been singled out for abuse. HIV- and AIDS-related murders have increased in a range of developing countries (Parker and Aggleton, 2002a).

Families and friends of PLHAs often experience secondary stigma. In South Africa, this process has exacerbated the erosion of communal values among Africans, including the support provided by the extended family. One effect is that the care of orphans has become a major challenge to communities (Brown, MacIntyre, and Trujillo, 2002).

Another effect of stigma is that regardless of HIV status, employees working in HIV/AIDS programs may be seen by community members as HIV positive and discriminated against. One case cited in the research literature is that of a woman who was denied the blessing of her marriage ceremony by a pastor because of her involvement in HIV/AIDS work (UNAIDS, 2002a).

The most prominent form of discrimination in the workplace is in the form of termination of employment or refusal to offer employment, based on employees' alleged HIV status (UNAIDS, 2000a). This is most often linked to employers' unnecessary fears about the transmission of HIV in the workplace. There is also extensive evidence that workers who are open in the workplace about their HIV status are more likely to experience stigma and ostracism from colleagues (Panos Institute, 1990; UNAIDS, 2000a).

The stigma associated with HIV/AIDS in the workplace has been linked to senior management's reluctance to give priority to HIV/AIDS programs. The success of HIV/AIDS workplace programs has often been associated with an individual in a company who happened to be passionate about the subject but who is then perceived by other employees as infected with HIV, irrespective of the truth (Richter, 2001).

In South Africa, the AIDS Law Project has documented numerous discriminatory acts regarding HIV/AIDS in the workplace. Cases of exclusion from employee benefits, nonconsensual pre-employment HIV screening, and nonconsensual disclosure of HIV status have been widely reported despite the existence of legal protection (Richter, 2001). Domestic workers are especially vulnerable to stigma, given their limited protection by the law and employers' anxieties about employing an HIV-positive person in the home—particularly where young children are present.

A study conducted by CADRE (2002) found that most companies' human resource managers, despite offering adequate medical benefits, did not know about the services that insurance companies offered to employees living with HIV/AIDS. Ignorance in the workplace is also reflected by the lack of policies defining the employer's responsibilities toward PLHAs and protection from discrimination by others, limited or no budgetary allocations for HIV/AIDS programs, and failure to commit time for employees to participate in AIDS awareness campaigns. This appears to be a more significant problem in the developing world.

Finally, HIV/AIDS programs themselves may unwittingly contribute to the development of stigma (Parker and Aggleton, 2002a). It has been suggested, for example, that government HIV/AIDS prevention programs are often targeted to the so-called "general population," often omitting mention of high-risk populations such as gay and bisexual men or sex workers. In so doing, these groups are implicitly labeled as less important or of lower priority. This reproduces pre-existing stigmatization of such groups.



## **HIV/AIDS Stigma and the POLICY Project's Response**

In 2002, there was an increased recognition that having significantly more direct understanding and data regarding HIV/AIDS stigma (as opposed to anecdotal evidence and comparable evidence from other areas of health) was an absolute requirement for sound decisionmaking, policy development, and practical strategic design for HIV/AIDS programs.

Initiatives aimed at reducing the prevailing climate of stigma and discrimination were all too often only focused on the creation of nondiscriminatory supportive national policies. While this is an important component, policy alone cannot reduce HIV/AIDS stigma and discrimination, much of which has been internalized by PLHAs. Moreover, programs that aim to empower PLHAs and increase their involvement in the fight against the epidemic have been small, scattered, and not systematically documented and evaluated. It was, therefore, imperative that we simultaneously focus on the practical concerns and impact of both external and internal stigma and discrimination as they affect people's choices and life decisions, in real terms and in real lives.

In its multilevel approach to stigma and discrimination, and its focus on increased involvement of PLHAs, this core package explored new approaches to stigma and discrimination. More specifically, this package offered the chance to identify indicators of stigma, which HIV/AIDS program managers could use as the basis for the design and evaluation of global prevention and care initiatives.

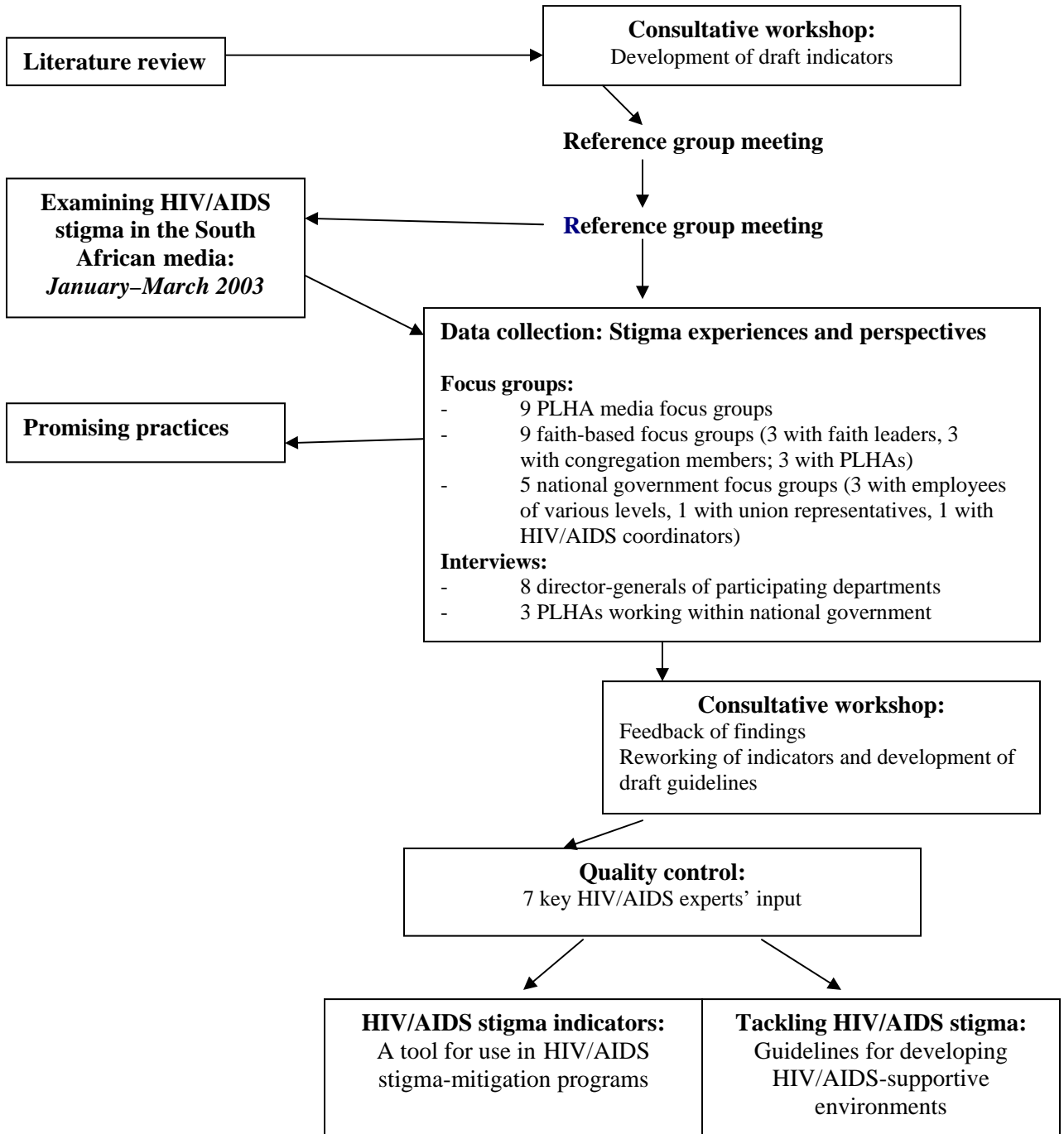
The POLICY strategy involved the following interrelated activities:

- *The development of an information base:* Specific documents were compiled to inform the project through a literature review and a media scan. The literature review provided a synthesis of theoretical understandings of stigma. This information was complemented by a media scan, which provided a context to locate the fieldwork in a particular time and place.
- *A qualitative exploration of stigma experiences and perspectives:* Focus group discussions and key informant interviews across South Africa helped develop indicators of internal and external stigma. Furthermore, guidelines were established to assist those who wish to develop interventions that will have a positive impact on HIV/AIDS stigma. Finally, documentation of promising practices that mitigate HIV/AIDS stigma was developed.

The research was conducted in the following three sectors:

1. Faith-based organizations and communities as important sources of support to PLHAs
2. Government departments as workplaces committed to dealing with stigma through good policy and practice
3. The relationship between PLHAs and the media as an example of how empowered individuals can have a positive impact on perceptions and attitudes toward HIV/AIDS

## Overview of Activities Under the Core Package



## **Overview of the Research Process**

The development of indicators of stigma and guidelines to tackle stigma were developed based on fieldwork that consisted of the collection of HIV/AIDS-related stigma experiences and perceptions from a group of 182 participants who participated in 23 focus groups (conducted across all nine provinces of South Africa) and 11 in-depth interviews. The purpose of the fieldwork was to collect a wide range of experiences of HIV/AIDS-related stigma to serve as inputs to the development of indicators that would enable measurement of progress in stigma-mitigation projects. In addition, seven telephonic interviews were held with key informants as a means of quality control (see Figure 1 for an overview of the research process).

Experiences of representatives from three sectors—faith-based organizations, government workplaces, and the media—were collected during focus group discussions. These three sectors were specifically chosen as they were considered to represent institutions that people look to for leadership, and they are also institutions that have the power to shape people’s perceptions and responses. To capture the complexity of HIV/AIDS-related stigma, a qualitative exploration of experiences of HIV/AIDS in these three sectors was conducted. A focus group approach was viewed as most appropriate as it allows participants to explore the perceptions and experiences of HIV/AIDS-related stigma through discussion.

An effort was made to ensure that the participants were representative of the South African population by organizing focus groups in all nine provinces and targeting both men and women from all racial groups. Of the focus group participants, 85 percent were black, 55 percent were women, and 43 percent were PLHAs. The number of participants in the groups varied, ranging from four to 12 participants. Participation was voluntary, but participants were given money to cover their transport costs.

The data collected through the interviews and focus groups were used to refine the draft indicators and to prepare guideline documents for the design of stigma-mitigation interventions for the three sectors.

## **Overall Approach**

The USAID-funded POLICY Project adopted a participatory, consultative approach to inform all aspects of the research. The implementation of the project was managed by the Centre for the Study of AIDS (CSA) at the University of Pretoria. Critical support was provided by the Chief Directorate HIV, AIDS and TB at the National Department of Health. Insideout, an independent research organization, conducted the fieldwork for this research.

To achieve greater participation by other stakeholders, four reference groups were established. Three of the reference groups consisted of representatives of the three selected sectors, and the fourth consisted of a group of experts with broad HIV/AIDS experience. The reference groups offered guidance and support for the overall project and facilitated partnerships with collaborating institutions. Each reference group held five meetings during the study period and email correspondence was ongoing.

Two consultative workshops were held. The first consultative workshop was held in November 2002 to develop draft indicators. Eighteen representatives participated, including representatives of the CSA, POLICY Project, the four reference groups, and a number of AIDS experts. The second consultative workshop was held in July 2003 to present the draft indicators and guidelines to the stakeholders who participated in the first workshop and to collect their input in order to refine the documents.

Organizations that participated in this study included AIDS Law Project; CADRE; Department of Health: Chief Directorate HIV, AIDS and TB; Department of Public Service and Administration (DPSA); Faith Organizations in HIV/AIDS Partnership (FOHAP); HOPE worldwide; Human Sciences Research Council (HSRC); Interdepartmental Committee on HIV and AIDS; National Association of People Living with HIV/AIDS (NAPWA); Positive Muslims; Southern African Bishops Conference; SOWETO HIV/AIDS Counsellors Association (SOHACO); Statistics South Africa; The Anglican Church; Tsabotsoso; United Nations Development Program–The Greater Involvement of People Living with HIV/AIDS (GIPA) Project; and University of Pretoria–School of Health Systems and Public Health.

## **Endorsement**

The project needed to obtain endorsement for the study from representatives of all three sectors. The relevant national and provincial heads of Christian faith groups—which included the Catholic, Anglican, Methodist, United Presbyterians, and Dutch Reformed faith groups—were approached to endorse the study and asked to identify possible faith leader participants as well as faith leaders who could be approached to identify congregation members in each of the provinces. The Muslim Judicial Council and a community-based HIV/AIDS organization, Positive Muslims, were approached as representatives of the Islamic faith to endorse the study.

With the support of the Chief Director of the Chief Directorate: HIV, AIDS and TB in the National Department of Health, the *Siyam'kela* Project obtained the necessary endorsement from DPSA. DPSA requested relevant departments to participate in the project. The project also received support from the government's Interdepartmental Committee on HIV/AIDS and USAID (South Africa). NAPWA also gave its endorsement and support to the project by inviting PLHAs in each of the nine sectors to attend focus group discussions.

## **Measurement Tools**

Discussion guides were developed for the focus groups in each of the three sectors and their respective subgroups. Interview schedules were developed for the various interviews:

- Interviews with the director-generals—or their representatives—were structured interviews.
- Interviews with the PLHA employees working for national government departments were based on the focus-group discussion guides, which explored

their experiences of HIV/AIDS-related stigma and the extent to which their working environment supported them.

- Quality control interview schedules were open-ended with the aim of exploring feedback from the participating experts after they had reviewed the draft indicator and guideline documents.

## **Participant Selection and Data Collection**

*Media.* A total of 59 PLHAs (23 females and 36 males) in the nine focus groups shared their experiences of interacting with the media. Focus groups were held in each of the nine provinces. An effort was made to keep the focus groups homogenous with regard to race and gender so that participants could feel free to comment honestly on their experiences of HIV/AIDS stigma and to explore how race and gender might differently affect their experiences. The criterion of having interacted with the media made it difficult to locate a sufficient number of participants in each province.

*Faith sector.* Focus groups were held within the faith sector—one in each of the nine provinces. The research focused on three subgroups within the faith sector, namely faith leaders, congregation members, and PLHAs who belonged—or used to belong—to a faith group. In some cases, faith leaders (from both the Christian and Islamic faiths) were not ordained leaders but rather opinion leaders working on HIV/AIDS within the church setting. Opinion leaders were lay persons belonging to a faith-based organization who were responsible for conducting various HIV/AIDS initiatives within their congregations. The opinion leaders who participated in the focus groups had a deep level of understanding of issues related to HIV/AIDS. They had a strongly influential voice about HIV/AIDS issues within the structures of their faith-based organizations.

Three focus groups were conducted within each subgroup. Participants were drawn from the Christian faith (including the Catholic, Anglican, Methodist, United Presbyterian, and Dutch Reformed churches) and the Islamic faith. According to the 1996 South African census, these faith groups represented the majority of the South African population. The African Zionist faith group, which also has a large membership in South Africa, was also targeted. However, the researchers were unable to find any participants for the study from this group.

Faith leaders identified congregation members to participate in focus groups. NAPWA provincial offices, Positive Muslims, and the Islamic Careline identified PLHA participants for the faith focus groups. Positive Muslims and the Islamic Careline identified faith leaders, congregation members, and Muslim PLHA participants countrywide. A total of 25 faith leaders, 31 congregation members, and 20 PLHA congregation members participated in the focus groups.

*Government workplace sector.* The national government was selected as an example of a workplace setting. Three focus groups were held with employees from different levels within the public sector, namely cleaner (level 1) to deputy directors (level 12). The two remaining focus groups included representatives of the National Education, Health and Allied Workers' Union (NEHAWU) and national government HIV/AIDS coordinators. All government departments were invited to participate in the study. An effort was made

to include representatives from each of the participating departments in each workplace focus group, including Agriculture, National Treasury, the Presidency, the Public Service Commission, the South African Police Service, Land Affairs, Correctional Services, Housing, Justice, Arts and Culture, Science and Technology, and Social Development.

In addition to the focus groups, eight in-depth interviews were conducted with director-generals—or their nominated representatives—from the participating departments. Four key informant interviews were conducted with PLHAs working in different government departments. A total of 12 senior managers, 11 middle managers, 11 junior managers, 10 HIV/AIDS coordinators, and three union representatives participated in these focus groups.

## **Analysis**

The focus groups held in each of the three sectors (faith groups, media, and national government workplace) were analyzed separately. Each of the subsectors within these sectors was also analyzed separately. For example, in the faith focus groups, faith leaders, congregation members, and PLHA members of faith groups were, therefore, analyzed separately. Once themes emerged, the various subsectors were analyzed for their differences and similarities.

Content analysis was used to analyze the transcripts. All information was analyzed in terms of emerging themes. Common patterns were identified and categories grouped into broad emerging themes, which were then grouped into sections related to environment, internal and external stigma, and perceptions of HIV/AIDS. The research team cross-checked the analysis to verify the categories and subcategories.

Based on the findings, draft indicators to measure external and internal HIV/AIDS stigma and draft guidelines for stigma-mitigation interventions were drafted. Special attention was given to issues of gender and race in the analysis.

## **Quality Control Interviews**

Participants for the quality control interviews were selected based on their HIV/AIDS expertise. Seven telephone interviews were held with HIV/AIDS experts to discuss the preliminary indicators and guidelines that emerged from the focus group findings. Respondents included two PLHAs, one member of a faith-based organization, one government official, two HIV/AIDS specialists with broad experience, and one gender and HIV/AIDS expert. In addition, two representatives of faith groups, one person from the national government, and one HIV/AIDS specialist with broad experience provided written feedback on the draft guidelines and indicators, respectively.



## **Findings from the Field: HIV/AIDS Stigma Indicators and Guidelines**

An overall finding from the research was that stigma affects men, women, and different race groups differently. The perception of HIV/AIDS as a woman's disease and as an African disease emerged strongly from the focus groups.

The perception of HIV/AIDS as a women's disease was mainly as a result of antenatal services in the public sector routinely testing pregnant women, with their consent, for sexually transmitted infections (STIs), including HIV. Since women access these services, they discover their HIV-positive status first. Thus, they have the burden of sharing the information with their male partners. More specifically, HIV/AIDS is perceived to be an African women's disease, as private hospitals do not routinely test pregnant women for HIV, and it is usually African women who access public healthcare services. The higher one's socioeconomic status, the easier it is to hide one's HIV status. Those who have the means to afford ARV treatment and live a healthy life can conceal their HIV status.

### **1. HIV/AIDS Indicators: Findings and Proposed Indicators**

This core package developed and documented a number of indicators of stigma in a publication called *HIV/AIDS Stigma Indicators: A Tool for Measuring the Progress of HIV/AIDS Stigma Mitigation*. The findings are arranged into themes, and these themes have been clustered according to indicators of internal or external stigma. A summary of the findings and the indicators follow.

#### ***External Stigma***

##### **Avoidance**

*Finding.* PLHAs reported being *avoided* by others, often because of a fear of casual transmission of HIV or because of a perception of PLHAs as immoral and dirty. Avoidance usually took the form of not wanting to share items with PLHAs, such as chairs, utensils, toilets, and so forth. PLHAs also mentioned experiences of people avoiding spending time with them or not wanting to be in close proximity to them.

##### ***Indicators***

- Number of PLHAs who report cases of others not sharing objects with them
- Number of PLHAs who report cases of others who distance themselves from them socially
- Number of PLHAs who report an experience where they feel like others reduce them to the virus and no longer see them as a whole person
- Number of PLHAs who report cases of others who distance themselves from them physically
- Number of PLHAs who report cases of others gossiping behind their backs
- Number of people who would not share objects with PLHAs
- Number of people who would distance themselves socially from PLHAs
- Number of people who would distance themselves physically from PLHAs

- Number of reports of people distancing themselves from PLHAs from affected friends and family

## **Rejection**

*Finding.* Many PLHAs have suffered rejection from their spouses, families, friends, and colleagues because of the perception that PLHAs deserve the illness or that HIV can be transmitted through casual contact.

### *Indicators*

- Number of PLHAs who have been abandoned by significant people in their lives
- Number of PLHAs who were pressured to leave their organization/social setting after publicly disclosing their status
- Number of PLHAs who were pressured to leave their place of residence
- Number of people who would abandon significant people in their lives if they found out that they were HIV positive
- Number of people who feel that PLHAs should not be welcomed within their organization/social setting
- Number of people who feel that PLHAs would not be welcomed in their homes

## **Moral judgement**

*Finding.* Some participants made an association between HIV and immoral sex or promiscuity. People who contracted the virus through sexual contact outside the norms of society were seen as “guilty.” PLHAs reported that they were often perceived to have been promiscuous and, consequently, “guilty” or blamed for their status. According to PLHAs, the immediate assumption people make when they disclose their status is that they are people with “loose morals.” Some participants reported that how a person contracted HIV informed others’ responses to the PLHAs. According to participants, a person was considered “innocent” if they were passive or powerless in contracting HIV, for example rape survivors, children born to parents living with HIV, and those who contracted the virus through a blood transfusion or needle prick. Few participants challenged the notions of “innocent” and “guilty” victims of HIV/AIDS—even in the PLHA focus groups. However, a few of the PLHA participants challenged the notion of “innocence” and “guilt” in contracting HIV, as no one “deserves” HIV and, therefore, everyone is “innocent.” These participants felt that it was not an issue of “innocence” or “guilt,” but rather the personal responsibility of each person to practice safe sex. Some male and female participants viewed women as “innocent victims” of HIV/AIDS because of their physical and social vulnerability in terms of power in negotiating sexual relationships and the use of condoms.

### *Indicators*

- Number of PLHAs who report cases of others using the concept of blame in responding to them
- Number of PLHAs who report cases of others who present HIV/AIDS in terms of a moral judgment
- Number of people who use the concept of blame in relation to PLHAs
- Number of people who present HIV/AIDS in terms of a moral judgment

### **Stigma by association**

*Finding.* As a result of the silence surrounding HIV/AIDS and the fear of casual transmission, a culture of suspicion has developed in which people try to identify possible PLHAs through association. The most commonly suspected symptom of HIV/AIDS was weight loss. If the cause of death is not specified, such as a heart attack, car crash, or shooting, then it is assumed that the person died of an AIDS-related illness. PLHAs were accused of lying about their status, as there was the perception that a healthy person could not be living with HIV/AIDS. Other symptoms associated with HIV/AIDS included mental illness, skin conditions, TB, and pneumonia.

Some employees did not even want HIV/AIDS posters in the office because they did not want to be associated with HIV/AIDS in any way. Some participants mentioned that wearing HIV/AIDS t-shirts, ribbons, or brooches had become stigmatizing, as some people believed that only PLHAs wore such items. In addition, rape survivors were also stigmatized due to the association between rape and contracting HIV/AIDS. People from certain geographical areas, such as rural areas, were also stigmatized if there was a high rate or a perceived high rate of HIV infection in that area. Another example was the close association between HIV/AIDS and mining communities in South Africa, where HIV is prevalent.

In addition, many PLHAs described stigma that their children or partners were exposed to because of the PLHA's HIV status. There was also the assumption that family members or partners of PLHAs were also living with HIV/AIDS. Therefore, according to participants, a key issue PLHAs need to carefully consider when disclosing, especially to the media, is the effect it might have on family and friends because of stigma by association. As a result, some family members of PLHAs encouraged nondisclosure because of their own fears of stigmatization.

#### *Indicators*

- Number of PLHAs who report cases of others who stigmatize those who are associated with them
- Number of people within an organization/social setting who stigmatize individuals based on associations related to HIV/AIDS
- Number of people who report having been stigmatized by others as a result of their association with HIV/AIDS

### **Unwillingness to invest in PLHAs**

*Finding.* In some cases, people claimed that they would not disclose if they learned that they were living with HIV/AIDS for fear that they would be marginalized within their organization. This refers to not receiving training and development or being promoted. It also means that they feared they would be given less responsibility after disclosing.

#### *Indicators*

- Number of PLHAs who are marginalized within their organizations after having disclosed their HIV status, despite adequately performing their assigned roles
- Number of leaders within an organization who would not consider investing in openly disclosed PLHAs

## **Discrimination**

*Finding.* PLHAs reported being unable to access services solely on the basis of their HIV status, including life insurance and funeral coverage, medical plans, and blood transfusions. This severely hampered their quality of life and peace of mind. PLHAs accessing health services did not always receive the same care and courtesy that other patients received. Furthermore, staff did not trust workplace HIV/AIDS policies because not many people had openly disclosed their status, thereby “testing” policy implementation.

### *Indicators*

- Number of PLHAs who have been denied services because of their HIV-positive status
- Number of people who would deny services to an HIV-positive person
- Number of reported cases of HIV/AIDS-related stigma and discrimination in the organization/social setting

## **Abuse**

*Finding.* PLHAs reported instances of abuse by others because they were perceived as immoral or a threat to the community. Verbal abuse and name calling was a more common form of external stigma than physical abuse. However, at times PLHAs were threatened with physical violence or their lives were threatened. Other incidents of abuse reported by PLHAs included the beating of wives who disclosed, throwing condoms at PLHAs, and being called “Satan’s people” at church. According to participants, women are more vulnerable to physical abuse by their intimate partners, as participants mentioned cases of women being physically assaulted by their partners when disclosing their HIV-positive status.

### *Indicator*

- Number of PLHAs who have been verbally abused as a result of their HIV status
- Number of PLHAs who have been physically abused as a result of their HIV status
- Number of people who think that verbal abuse of PLHAs is justified
- Number of people who think that physical abuse of PLHAs is justified

## **Internal Stigma**

### **Self-exclusion from services and opportunities**

*Finding.* Some PLHAs had chosen not to seek services or opportunities because of their fear of stigmatization. These included support groups, material assistance programs, and clinical services.

### *Indicators*

- Number of PLHAs who choose not to access existing support services
- Number of PLHAs who choose not to apply for a job because of their fear of being exposed as HIV positive

### **Perception of self**

*Finding.* PLHAs seem to be more vulnerable to internalizing stigma after being diagnosed with HIV if they have poor personal coping mechanisms, are within a nonsupportive environment, or have past experience of external stigma and discrimination. Overall, internalized stigma creates the belief in some PLHAs that they have become less valuable and worthy within society because of their “unclean” state. Should a PLHA be part of an already stigmatized group, this stigma may only reinforce these internalized beliefs about worth. These perceptions reflect society’s beliefs and the stigma of the disease. This includes perceiving oneself as less valuable than HIV-negative people, as a disappointment to others, as guilty and immoral, or as a threat to others’ health.

Some participating PLHAs described that they felt they had disappointed others because of their HIV status. Internalized stigma can result in PLHAs feeling as though they have brought shame upon their family and community. This sense of having disappointed others is a reflection of the internalized societal beliefs regarding guilt and responsibility for HIV infection.

#### *Indicator*

- Number of PLHAs who have low self-esteem as a result of their HIV-positive status

### **Social withdrawal**

*Finding.* PLHAs may perceive the need to withdraw socially in order to protect themselves (and/or their family and friends) from stigmatization and discrimination. This kind of self-imposed isolation has led to some PLHAs excluding themselves from sexual and loving relationships. Others chose to only spend their time with other PLHAs, thinking that they will not stigmatize or discriminate against them. In other words, some PLHAs may withdraw from HIV-negative people. Also, the fear of being judged and “exposed” has led some PLHAs to not apply for jobs.

#### *Indicators*

- Number of PLHAs who have fewer interactions with people than before they learned of their HIV status
- Number of PLHAs who choose not to have intimate relationships
- Number of PLHAs who have fewer interactions with HIV-negative people

### **Overcompensation**

*Finding.* PLHAs may perceive the need to overcompensate in terms of their behavior in order to protect themselves from stigmatization and discrimination. PLHAs may also overcompensate because of internalized stigma. Other forms of overcompensating behavior include PLHAs feeling as though they need to prove to their faith congregations that they are good people. Some PLHAs have done this by attending church regularly and by asking for an opportunity to prove themselves. Some PLHAs may feel that it is important to address the stigma associated with HIV/AIDS in relation to their worth as employees by working much harder than other colleagues as a means of proving themselves.

### *Indicators*

- Number of self reports from PLHAs (GIPA placements) who believe they contribute more than HIV-negative people as a means of proving themselves
- Reports from managers who employ PLHAs

### **Fear of disclosure**

*Finding.* According to most PLHA participants, disclosing their HIV-positive status was very difficult, with their greatest fear being judged and rejected from their families, spouses, and the wider community. This fear was based on what people have seen happen to others in their communities. As a result, many PLHAs do not disclose their HIV status. When participants who were not PLHAs were asked if they would disclose their status if they were living with HIV, many said they would not due to fear of discrimination at work—not being promoted, being viewed as a burden on the work team, and being seen as less competent and reliable than other staff. Participants were more likely to disclose to their immediate family and partners than at work or in public. Female participants, in particular, were concerned about disclosing their status to their children. It seemed to be slightly more of an issue for women than for men. The association of HIV/AIDS and promiscuity is one of the reasons for the difficulty in disclosing to children.

### *Indicators*

- Number of PLHAs who have disclosed their status
- Number of PLHAs who are willing to publicly disclose their status to the media
- Number of people who would not disclose their HIV-positive status due to fear of stigmatization

## **2. Guidelines to Address HIV/AIDS Stigma**

The guidelines from the research were developed to increase awareness among decisionmakers in the workplace of the importance of creating an accepting environment to reduce HIV/AIDS stigma and to provide recommendations on how to foster this environment.

The following documents were prepared based on the research:

- Tackling HIV/AIDS Stigma: Guidelines for the Workplace
- Tackling HIV/AIDS Stigma: Guidelines for Faith-based Organizations
- Tackling HIV/AIDS Stigma: Guidelines for People Living with HIV/AIDS Who Interact with the Media

### ***Tackling HIV/AIDS Stigma: Guidelines for the Workplace***

The guidelines highlighted the importance of a supportive policy environment, good leadership, and focused interventions.

Recommendations for creating a supportive policy environment:

- a) Conduct an HIV/AIDS policy analysis
- b) Inform employees of HIV/AIDS stigma-mitigation policies
- c) Mainstream HIV/AIDS stigma-mitigation policies
- d) Monitor the implementation of policies

HIV/AIDS program managers need to ensure that management

- a) Mainstreams HIV/AIDS mitigation interventions
- b) Get involved in HIV/AIDS programs
- c) Has the capacity to give effective anti-stigma messages and plan effective HIV/AIDS strategies
- d) Includes PLHAs in positions of leadership

With the design and development of interventions, program managers should consider the importance of the following:

- a) Conducting a stigma audit to understand the extent of stigma and the local barriers and factors that enhance stigma.
- b) Involving PLHAs in policy development and the implementation and monitoring of programs. Trained PLHAs will then be seen as positive role models.
- c) Providing staff with training to sensitize them to HIV/AIDS stigma.
- d) Making the care and support of PLHAs visible.
- e) Focusing interventions on behavior change and not just on provision of information.
- f) Spreading HIV/AIDS stigma-mitigation messages year-round, not just at World AIDS Day events.
- g) Using positive images of PLHAs in awareness programs.
- h) Monitoring interventions for their sensitivity to stigma mitigation.

### ***Tackling HIV/AIDS Stigma: Guidelines for Faith-based Organizations***

The guidelines highlighted the importance of a supportive policy environment, good leadership, focused interventions, and strong partnership.

With regard to policy, faith-based organizations need to

- a) Develop guidelines that will assist faith leaders, as well as congregants, in appropriately dealing with HIV/AIDS and related stigma
- b) Mainstream HIV/AIDS stigma-mitigation guidelines into faith-based policies
- c) Encourage open discussion about how to maintain confidentiality within a faith community

Faith-based leaders need to

- a) Receive ongoing capacity building in stigma mitigation
- b) Take responsibility to implement stigma-mitigation interventions and monitor their effectiveness
- c) Be involved and committed to stigma mitigation at all levels
- d) Involve PLHAs in positions of leadership

The following actions should be undertaken to intervene appropriately

- a) Assess the extent of stigma in the faith-based community
- b) Involve PLHAs as positive role models
- c) Deliver appropriate prevention messages
- d) Raise awareness of HIV/AIDS stigma in faith communities

- e) Provide training that is aimed at behavior change and not limited to information only
- f) HIV/AIDS stigma-mitigation messages should be spread year-round and not be limited to World AIDS Day events
- g) Use positive images of PLHAs in awareness programs
- h) Monitor interventions for their sensitivity to stigma mitigation

Lastly, the guidelines highlight the importance of partnerships so that faith communities strengthen their existing partnerships, develop new partnerships, and therefore make referrals to existing service providers where appropriate.

***Tackling HIV/AIDS Stigma: Guidelines for People Living with HIV/AIDS Who Interact with the Media***

This set of guidelines addresses the role of PLHAs who work with and interact with the media. This set of guidelines

- a) Highlights and supports the involvement of PLHAs throughout the process of developing of an HIV/AIDS story/article found in print media, the radio, or television. The guidelines recognize and encourage PLHAs to become empowered to interact with the media in an assertive manner to ensure an outcome that is a true reflection of the story shared.
- b) Encourages that PLHAs need to advocate that media regulatory bodies accept media ethical guidelines.
- c) Encourages the development of HIV stigma-mitigation messages.
- d) Encourages PLHA organizations to be trained in working with the media.



## Summary

The POLICY Project, through this core package, has created a dialogue focused on HIV/AIDS stigma. This has been achieved through the findings and tools developed from the research, as well as through the participatory manner in which the research was conducted. The core package has created an opportunity to raise significant awareness at local, national, and international levels. The project developed a number of HIV/AIDS stigma indicators and guidelines. The content for the 23 focus group discussions yielded 12 inter-connected themes, broadly categorized as external and internal stigma. The overarching themes common to all forms of external stigma were excluding PLHAs and judging them as less valuable than people who are HIV negative. These themes emerged from the thoughts and experiences of people who are living with HIV/AIDS and those who are not necessarily HIV positive but located in faith communities and national government departments.

The various manifestations of internalized stigma are the result of internalizing the negative responses of others. The themes included PLHAs removing themselves socially and from services to avoid rejection or because they considered themselves less valuable as a result of their infection. These themes emerged from the experiences of 81 PLHAs.

The themes to emerge from the above discussions were significant in that they formed the basis for the development of a set of indicators for measuring stigma-reduction programs, as well as a set of guidelines for PLHAs (with respect to their engagement with the media), for faith communities, and for national government departments regarding how they could mitigate HIV/AIDS stigma.

This research project has enriched all who have worked on it. Thanks are due to all of the participants for their valuable contributions to the *Siyam'kela* Project. Special thanks are due to the many people living with HIV/AIDS who shared their stories of overcoming difficulties and moving toward personal acceptance.

It is hoped that as a result of the participatory nature of this project, the resulting reports will be interesting and useful and will assist in mitigating HIV/AIDS stigma.

It is recognized that these processes are dynamic and we encourage others to test the outcomes from this core package and to revise and modify them where necessary.



## **POLICY's Impact and Future Perspectives**

Despite the completion of this core package, the project continues to grow and flourish, with the outcomes being taken to another level. The research project has received the ongoing support of USAID/South Africa and the Chief Directorate: HIV/AIDS and TB at the National Department of Health. This has allowed the team to build on the findings and outcomes of the core package. In the next phase, the indicators will be tested, training interventions developed, and people at all levels will be trained and oriented to the importance of mitigating stigma as part of a successful comprehensive strategy toward HIV/AIDS prevention and care.

In addition, all the documents are being used by organizations locally—and presentations and training are being offered where possible. Internationally, the indicators have been used to assist in the identification of stigma indicators for the USAID Expanded Response Guide as well as for the President's Emergency Plan for AIDS Relief. The project will remain dynamic and responsive to the needs of HIV/AIDS programs at all levels.



## References

- Advocacy for Action on Stigma and HIV/AIDS in Africa. 2001. Regional consultation meeting on stigma and HIV/AIDS in Africa, June 4–6, 2001.
- Bollinger L. 2002. *Literature Review of General and HIV-related Stigma*. Washington, DC: POLICY Project.
- Brown L., K. Macintyre, and L. Trujillo. 2002. *Interventions to Reduce HIV/AIDS Stigma: What Have We Learned?* Washington, DC: Population Council.
- Campbell, I.D. and A. Rader. 2002. “HIV/AIDS, Stigma and Religious Responses: An Overview of Issues Relating to Stigma and the Religious Sector in Africa.”
- Centre for AIDS Development, Research and Evaluation (CADRE). 2002. *What’s News? Perspectives on HIV/AIDS in the South African Media*. Johannesburg: CADRE.
- Council of Anglican Provinces in Africa. 2002. Statement from CAPA AIDS Board meeting, August 19–22, 2002.
- Department of Health. 2004. National Baseline Assessment of STI and HIV Services in South African Public Sector Health Facilities 2002–2003. Johannesburg: Department of Health.
- Department of Health. Released 2003. *National HIV and Syphilis Sero-prevalence Survey of Women Attending Public Antenatal Clinics in South Africa 2002*. Johannesburg: Department of Health.
- Department of Health. 2002a. *Discrimination and HIV/AIDS*. Strategy and Tactics. Johannesburg: Department of Health.
- Department of Health. 2002b. *Khomanini: Reaching out–Scaling up. Report of the First South African National Home/Community-Based Care Conference*, September 18–21, 2002.
- Faith in Action National Indaba. 2002. *Faith in Action: A United Response to HIV/AIDS*. Durban, March 5–6, 2002.
- International Center for Research on Women (ICRW). 2002. *Addressing HIV-related Stigma and Resulting Discrimination in Africa: A Three-Country Study in Ethiopia, Tanzania and Zambia*. Washington, DC: ICRW.
- Manser, M. and M. Thomson (eds.). 1999. *Combined Dictionary Thesaurus*. Edinburgh: Chambers.

- Panos Institute. 1990. *The Third Epidemic: Repercussions of the Fear of AIDS*. London: Panos Institute.
- Parker, R. and P. Aggleton. 2002a. *HIV and AIDS-related Stigma and Discrimination: A Conceptual Framework and Implications for Action*. Rio de Janeiro: ABIA and Thomas Coram Research Unit.
- Parker, R. and P. Aggleton. 2002b. *HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action*. New York: Horizons Program.
- POLICY Project. 2003. *Examining HIV/AIDS Stigma in Selected South African Media: January–March 2003, A Summary*. Cape Town: Siyam’kela Project.
- Population Council. 2002. *HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action*. New York: Horizons Program.
- Population Council. 1999. *Challenging HIV-related Stigma and Discrimination in Southern Asia: Past Successes and Future Priorities*. New York: Horizons Program.
- Richter, M. 2001. *Nature and Extent of Discrimination against PLWAs in South Africa*. Interviews and a Study of AIDS LAW Project Client Files, 1993–2001. Johannesburg: AIDS Law Project.
- Shisana, O. and L. Simbayi. 2002. Nelson Mandela/HSRC Study of HIV/AIDS: South African National HIV Prevalence, Behavioural Risks and Mass Media. Cape Town: Human Sciences Research Council.
- Soul City. n.d. *HIV/AIDS: A Resource for Journalists*. ISBN 1-919855-03-3.
- Terrence Higgins Trust. n.d. *Social Exclusion and HIV–A Report*. London.
- Thom, A. 2003. “Mother-to-child HIV transmission programme in trouble.” *Mail & Guardian Newspaper*.
- UNAIDS. 2002a. *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination*. Geneva.
- UNAIDS. 2002b. *Situational Analysis of Discrimination and Stigmatization against People Living with HIV/AIDS in West and Central Africa. Ethical and Legal Considerations*. Geneva: UNAIDS.
- UNAIDS. 5/09/2001. Speech by Peter Piot: “Stigma and discrimination fuel AIDS epidemic, UNAIDS warns.” Durban: UNAIDS.
- UNAIDS. 2000a. *A Human Rights Approach to AIDS Prevention at Work: The Southern African Development Community’s Code on HIV/AIDS and Employment*. Geneva: UNAIDS.

UNAIDS. 2000b. *Comparative Analysis: Research Studies from India and Uganda*. Geneva: UNAIDS Best Practice Collection.

Vitillo, R.J. 2002. "The Role of the Catholic Church in Meeting the Challenge of HIV/AIDS in Africa." Paper written for the Center for Strategic International Studies. Washington, DC.