# 6. STRATEGIES

Stigma may seem irreversible. Once assigned, it is difficult to erase. And some of the underlying "causes" of stigma – such as being HIV-positive, a woman, and a homosexual – cannot be changed. Nevertheless, there have been many instances where stigma associated with ethnicity, religious belief and even health condition has diminished or disappeared – many people in the United States are now proud of their Irish origins, while their ancestors were ashamed; many forms of Christianity in Europe that were once stigmatized are now part of the mainstream; and in many parts of the world people who suffer from Hansen's Disease (once known as leprosy) are no longer ostracized.

Because of the pivotal role they play in every society, health workers can make a major contribution to "reversing" stigma and discrimination to the point where being HIV-positive is no greater an impediment to an individual's well-being than the intrinsic health condition.

An effective response to HIV/AIDS-related stigma and discrimination in the health services requires a well-conceived strategy with the cooperation of all concerned, including health service staff and administrators, local and national authorities, people living with HIV/AIDS and concerned non-governmental organizations.

## 6.1. Needs analysis

Any response to stigma and discrimination in the health services, whether in a single hospital, a group of hospitals or nationwide, should be based on the understanding of the nature and extent of the problem. Ideally, a needs analysis would cover all the components of discrimination described in Section 2.3. However, such a comprehensive study is both time-consuming and beyond the resources of most health services. In such circumstances needs analysis can be limited to research that identifies the following issues. Such research is likely to comprise a combination of questionnaires, interviews and literature research:

*The Declaration of Commitment adopted by the United Nations General Assembly Special Session on HIV/AIDS in June 2001 highlights global consensus on the importance of tackling the stigma and discrimination triggered by the disease.*

*"By 2003, [nations should] ensure the development and implementation of multisectorial national strategies and financing plans for combating HIV/AIDS that address the epidemic in forthright terms; confront stigma, silence and denial; address gender- and aged-based dimensions of the epidemic; [and] eliminated discrimination and marginalization" (paragraph 37)*

*"By 2003, [nations should] enact, strengthen or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by, people living with HIV/AIDS and members of vulnerable groups, in particular to ensure their access to, inter alia, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality; and develop strategies to combat stigma and social exclusion connected with the epidemic" (paragraph 58)*

- Patients' experiences (distinguishing the experience itself, context and impact)
- Patients' perceptions
- Patients' recommendations, distinguishing the needs of specific groups, such as:
  - o Women
  - o Homosexual men (and other men who have sex with men)
  - o Injecting drug users
  - o Young people
- Health workers' knowledge, attitudes, and practices and understanding of human rights norms and standards in connection with HIV/AIDS, distinguishing between:
  - o Doctors
  - o Nurses
  - o Counselors
  - o Etc.
- Health workers' experiences with:
  - o Patients
  - o Colleagues
  - o Hierarchy of the organization where they work
- Health workers' recommendations, addressing the needs of:
  - o Doctors
  - o Nurses
  - o Counselors
  - o Etc.
- Recognition of the needs of HIV-positive health workers
- Existing projects designed to reduce stigma and discrimination in similar establishments
- Existence of relevant legislation, policy and guidelines

Some of these issues are covered by indicators drafted by UNAIDS to measure the existing stigma and discrimination in society as a whole (UNAIDS/Measure, 2001) and in the health services (UNAIDS 2002c). Depending on the setting (e.g. in one small hospital or in a city-wide review) such research can normally be carried out within one to three months. The results should identify the areas requiring urgent intervention. The results would also serve as baseline data while the research techniques can and should be modified as part of ongoing monitoring and evaluation of the projects that are developed.

## 6.2. Interventions

The following principles[21] should underpin all projects that seek to reduce stigma and discrimination in the health services:

*Central concepts:*

- Respect for the dignity and human rights of all individuals;
- Recognition of the complexity of stigma and discrimination;
- Awareness of the origins, components and impact of stigma and discrimination in society, including links between HIV/AIDS and other inequalities and injustices;
- Understanding of the origins, components and impact of stigma and discrimination in the health services;
- Recognition of health workers and of people with HIV/AIDS concerns; and
- Understanding gender issue – the way in which women and men may be discriminated in different ways or at different stages of the health care process;

*Planning requisites:*

- Needs analysis (see above)
- Clear identification of objectives
- Involvement at all stages of:
  - o Staff, including administration and HIV-positive staff
  - o People living with HIV/AIDS
  - o As appropriate, stigmatized or affected groups such as:
    - Men who have sex with men
    - Injecting drug users
    - Women
    - Young people
    - Etc.

[21] This section draws on a number of documents, including ICN 2003, UNAIDS 2002a and UNAIDS / HDN / SIDA 2001.

*Possible goals:*

- Staff receiving appropriate knowledge and skills
- Conspiracy of silence and secrecy broken
- Supportive and safer workplaces created
- Adequate supplies and protective equipment provided
- Increased access to post-exposure care and treatment
- Resources improved/streamlined:
  - o Human
  - o Financial
  - o Institutional
- Appropriate policy and guidelines[22] to govern interaction between health workers and patients, including:
  - o Codes of ethics
  - o Confidentiality guidelines
  - o Counseling guidelines
- Appropriate policy and guidelines to sustain staff welfare
- Mechanisms for monitoring and evaluating the implementation of policy and guidelines
- Recognition of and response to working conditions that make it difficult to maintain a code of ethics
- Means of enforcing the code of ethics that focuses on the transgression rather than the individual who transgresses[23]
- Reinforcement of the implementation of universal precautions[24]
- Recognition of and response to institutional issues which enable or encourage discrimination or which prevent or make difficult an effective strategy for reducing discrimination

*New systems must be carefully tested before they are put into practice. For example, in one hospital in Ukraine a new system of codes on patient records designed to promote confidentiality confused many health workers. Some reverted to writing 'HIV+' on reports which were then left open to public view at the registration desk. (Panos / UNICEF 2001)*

- Inclusion of the above principles in health professional training as well as health care settings

*Target audiences:*

- Identify different categories of clients and their respective needs
- Identify different categories of health workers and their respective needs

*Partnerships:*

- Establish partnerships with concerned organizations in and out of the health care system, including those representing:
  - o People living with HIV/AIDS
  - o Non-governmental organizations working in HIV care and prevention
  - o Affected groups, such as sex workers, mothers, and men who have sex with men
  - o Different branches of the health professions
  - o Local and/or national authorities, including the Ministry of Health
  - o International (multilateral and bilateral) organizations

*Methodologies and activities:*

- Training for all health workers, including information and building of practical and attitudinal skills[25]
- Development of guidelines and policies
- Establishment of non-stigmatizing HIV/AIDS clinics and wards
- Promotion of voluntary counseling, testing and care (including post-exposure prophylaxis) for all health workers
- Development of administrative systems, including referral and discharge, which do not stigmatize patients.
- Establishment of patient support groups
- Establishment of staff support groups
- Support for general and specialist professional associations in AIDS care

22 HIV/AIDS can be included in existing codes / guidelines, or codes / guidelines can be developed that apply to all health care contexts while explicitly including HIV/AIDS.

23 This approach takes into account the fact that some transgressions are the result of institutional failure (eg lack of appropriate training) rather than the fault of the individual(s) concerned.

24 It should be noted that limiting discussion of universal precautions to HIV/AIDS may reinforce rather than reduce stigma. (Bennett 1995)

25 All health workers should receive some training on HIV/AIDS; specialized training may be required for health workers who work primarily or exclusively with patients with HIV/AIDS.

- Providing mentors for personnel
- Development of simple, effective systems that maintain confidentiality at all levels
- Publication and widespread dissemination of policy, guidelines, training resources and other materials, in an appealing format

Where projects are scaled up, successes and failures must be clearly identified and appropriate changes made to the model. Meanwhile, all activities should comply with human rights norms, which should be supported by legislation addressing discrimination in the health services and elsewhere, as discussed in Section 6.3.

### 6.2.1. Early diagnosis

As indicated in Chapter 2, stigma has a strong negative impact on the prevention and care continuum. Stigma prevents individuals of coming forward for testing, and thus limits the number of people aware of their status, which implicitly adds fuel to stigma.

In a cycle of cause and effect, a reduction in stigma will encourage more people to come forward for testing, therefore, there will be an increased number of HIV+ receiving appropriate treatment at an early stage of the infection. Eventually if more people are detected and are open about their status, it is likely that stigma will decrease. Thus sensitive and appropriate campaigns that encourage widespread testing are not only beneficial in terms of individual and public health, but can be an important tool in stigma reduction. (Valdiserri 2002)

## 6.3. A multisectorial approach

While some reduction in stigma and discrimination in health care settings can be achieved in individual cases, interventions are much more likely to be successful when they are part of broader action taken in the community. If possible, these should include local and/or national government structures, the commercial sector, religious organizations, the media, etc. The initiative for such interventions may come from any of the mentioned institutions or the health services. Interventions should be wide-ranging and include activities as a public information campaign through billboards and the media, sensitization of leaders from different sectors in the community, development of legislation and / or policy etc. (see Section 4.2 above)

Ideally, a multisectorial approach includes strategies as advocacy, legislation, involvement and empowerment of people living with HIV/AIDS, community mobilization, responses to other factors that limit access to HIV prevention and health care (such as racism, sexism, poverty, etc), legal protection for people with HIV/AIDS, workplace education and involvement of religious leaders. (UNAIDS 2002a). Legislation should protect basic human rights, establish national monitoring mechanisms and include:

- Formulation of policies and legislation to protect people living with HIV/AIDS, incorporating the international standards and human rights norms;
- Formulation and establishment of national monitoring mechanisms of human rights and discrimination through the Ombudsman offices or other domestic human rights bodies;
- Dissemination of international human rights norms and standards that protect persons with HIV/AIDS against discrimination and other forms of human rights violations; and
- Dissemination among persons with HIV/AIDS, family members, non governmental organizations of information regarding the international mechanisms and remedies available before human rights commissions and courts.

### 6.3.1. Specific populations

A multisectorial approach is not only desirable but also essential, given that stigma regarding homosexual men, injecting drug users and women sex workers, pervade society as a whole. Interventions must therefore be developed which address the whole of society, similar to the Brazilian campaign to reduce homophobia (Section 4.2).

Vulnerable populations, including those that are less stigmatized, (e.g. youth), must be the target and co-developers of appropriate strategies. On the one hand, inclusion of such groups sends a message to those communities that their concerns are acknowledged and will be responded to; on the other hand, inclusion increases understanding among program designers of the

group's concerns. In many countries, support groups of people with HIV/AIDS have formed the backbone of a community response to the disease and have had significant influence on the response from district and national governments.

Furthermore vulnerable groups have often devised sophisticated analyses of and appropriate responses to the way in which their lives are affected by HIV/AIDS, which includes stigma and discrimination and the health services. These responses may be local, national or international. In Latin America, for example, such organizations as SIDALAC (AIDS Initiative for Latin America and the Caribbean), ASICAL (Association for Integral Health and Citizenry in Latin America), FUNSALUD (Mexican Fund for Health) and the Ecuador Equity Foundation have made significant contributions to the development of strategies that involve men who have sex with men at different levels of the response to HIV/AIDS.

## 6.4. Concerns

Given the complexity of HIV/AIDS-related stigma and discrimination – its many origins, its many manifestations and its wide-ranging impact – interventions designed to reduce the extent of the phenomenon may not always achieve their goals. Planned interventions should therefore take the following and among other issues into consideration:

- Confusion caused by apparently mixed messages, for example, saying that risk is negligible but suggesting the need to be hyper vigilant. Training and hospital policies may promote excessive use of precautions rather than rational practice.
- Focus on the phenomenon rather than the cause: for example: reassuring patients that confidentiality will not be breached, but not implementing appropriate systems of confidentiality; or providing support groups for staff faced with burnout but not addressing questions of long hours or insufficient resources
- Over-emphasizing the differences between HIV/AIDS and other diseases (many other diseases are fatal, transmitted through sex or drug injection and are stigmatized). "Emphasizing how AIDS is different from other diseases … may be counter-productive. AIDS must be threaded through curricula, and all aspects of nursing science and skill must be applied to AIDS care. Practicing nurses need help to make links between knowledge they already possess and its applicability to HIV disease." (Bennett 1995)
- Provision of services for one group rather than everyone affected by HIV/AIDS may not be helpful. In Zambia, anger was created by a project that provided HIV/AIDS-related services for sex workers but not for the community as a whole. (Panos/UNICEF 2001) In Cuba, people with HIV are reportedly concerned that stigma may be fuelled by the extra food rations they receive.

## 6.5. A changing profile

Early in this report it was noted that stigma and discrimination are not a static phenomenon but a process. Similarly, the profile of the HIV/AIDS epidemic has changed since it was first identified and it is likely to continue to change. This section examines some possible developments and the potential positive and negative impacts on stigma and discrimination in the health services.

- *Increasing access to antiretroviral drugs*
  *Positive*
  - May cause a reduction in stigma by changing the image of HIV as a fatal disease and enabling people with HIV to live a normal and productive life.
  - Health workers may feel more motivated as their efforts will have strong and long-term benefits for the health of the patients.

  *Negative*
  - In some countries increased or universal access may generate demand beyond the capacity of the health system, particularly ambulatory services, and result in increased burnout for health workers.

- *Increasing role of primary care services*
  *Positive*
  - Patients may no longer need to attend services identified as HIV/AIDS care, and may, therefore, feel less stigmatized.

  *Negative*
  - Without training, discrimination may increase, as primary care workers have less experience and less contact with patients with HIV/AIDS; some patients may fear disclosure of their status to the community, particularly when the service is close to their residence.

- *Increasing use of rapid HIV test*
  *Positive*
  - May motivate the health workers to improve care of people with HIV, as it represents an uncomplicated and quick way to determine serological status and allows prompt intervention.

  *Negative*
  - The test would be simple and quick which may make health workers careless about the confidentiality guidelines.
  - The test may be used outside traditional health care settings (for instance, by employers), which may make it difficult for health workers in such situations to keep high standards of confidentiality etc.
  - Surgeons, nurses and other health workers may be more likely to require unnecessary tests and to refuse or provide inappropriate treatment to those who test negative.

Changes in the profile of the epidemic, such as increased numbers of cases among the poor, women and youth may increase the stigma that these groups suffer (which is less virulent than against homosexual men, for example but still present). Poor people tend to be less involved in social organizations and are more likely to have their rights abused. Young people tend to be outspoken and demanding, which can trigger a contrary reaction from health workers; and women, as discussed above, tend to suffer preconceptions regarding their sexual behavior.

## 6.6. Resources

Many organizations have resources for tackling stigma and discrimination, although relatively few have focused on the health services. Such organizations include:

- ASICAL (Association for Integral Health and Citizenry in Latin America)
  http://www.sigla.org.ar/asical.htm
- Horizons Project
  https://www.popcouncil.org/hivaids/stigma.html
- International Council of Nurses
  *Nurses: Fighting AIDS Stigma, Caring for All,* (ICN 2003)
- UNAIDS
  - *Regional Consultation Report: Stigma and HIV/AIDS in Africa: Setting the Operational Research Agenda (UNAIDS/HDN/ SIDA 2001)*
  - *A conceptual framework and basis for action: HIV/AIDS stigma and discrimination (World AIDS Campaign 2002-2003) (UNAIDS 2002a)*
  - *Protocol for the identification of discrimination against people living with HIV (UNAIDS 2002c)*

*Section 7.4 also includes a number of potential resources.*

## 6.7. Conclusion

There is no doubt that HIV/AIDS-related stigma and discrimination persist in the health services of many countries. It is a complex phenomenon where the true extent of discrimination and its impact on individuals and communities remains unknown. While there is some evidence of increasing acceptance of people with HIV/AIDS in the health services, some groups still face high levels of discrimination. But whoever is affected, as long as the phenomenon persists, it will bring psychological and physical distress to the individuals affected and severely hamper HIV/AIDS prevention and care efforts in the community as a whole.

Furthermore, interventions that tackle stigma and discrimination in the health services not only affect people living with HIV. Well designed and implemented programs also support health workers, reducing stress levels from fear, ignorance and prejudice and enabling them to achieve a greater sense of satisfaction from caring for the men, women and children in their care. It is hoped that this review has contributed to that process.