

“Accelerating the Momentum in the Fight Against HIV/AIDS”

South Asia High-Level Conference

3-4 February 2003, Kathmandu, Nepal



Issues Paper 3

**HIV/AIDS RELATED DISCRIMINATION AND STIGMA IN SOUTH ASIA:
A VIOLATION OF HUMAN RIGHTS**

“Despite moderate but noteworthy progress in rolling back the spread of HIV in several countries, stigma and discrimination remain major barriers to reversing the AIDS epidemic. Stigma harms. It silences individuals and communities, saps their strength, increases their vulnerability, isolates people and deprives them of care of support. We must break down these barriers or the epidemic will have no chance of being pushed back. Responding to AIDS with blame, or abuse towards people living with AIDS, simply forces the epidemic underground, creating the ideal conditions for HIV to spread. The only way of making progress against the epidemic is to replace shame with solidarity, and fear with hope.”

–Dr. Peter Piot, Executive Director, UNAIDS

“We may have broken a wall of silence among policy makers and decision-makers. But there is a second wall of silence out there -- a wall that is keeping young people from learning about HIV, and stigmatizing those who have it. And unless that second wall of silence is brought down, all the hard-won gains of recent years will have been for nothing.”

–Carol Bellamy, Executive Director, UNICEF at the
African Religious Leaders' Assembly on Children and HIV/AIDS,
Nairobi, 10 June 2002

HIV/AIDS Related Discrimination and Stigma in South Asia:

A Violation of Human Rights

Introduction

Stigma and discrimination associated with HIV and AIDS are the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating impact. HIV/AIDS-related stigma and discrimination are universal, occurring in every country and region of the world. They are triggered by many forces, including lack of understanding of the disease, myths about how HIV is transmitted, prejudice, lack of treatment, irresponsible media reporting on the epidemic, the fact that AIDS is incurable, social fears about sexuality, fears relating to illness and death, and fears about illicit drugs and injecting drug use.

In many parts of South Asia, stigma and discrimination is routinely faced by people living with HIV/AIDS and their families. Many others are discriminated because of their sexual orientation and choice of professional occupation. This paper examines the role stigma and discrimination play in the spread of the HIV/AIDS epidemic in the context of South Asia. The most affected are people living with HIV/AIDS, especially women and young girls. Also greatly affected are women and girls in households with HIV, irrespective of their personal HIV status, despite them being the principal caregivers and sustaining the family. HIV/AIDS further reinforces stereotypes and fuels the already existing gender-based discrimination against girls and women in the South Asian region. Young people are often denied information on HIV/AIDS and have limited access to prevention and care services, even though half of new infections in the region occur among them. Orphans whose parents have died of AIDS often drop out of school due to stigma and discrimination faced by them at school. Many of them end up in streets and often are sexually exploited. In addition they face violence, and are vulnerable to trafficking, substance abuse and child labour.¹

The Declaration of Commitment, adopted by the UN General Assembly Special Session on HIV/AIDS in June 2001, in which all South Asian countries participated, highlights global consensus on the importance of tackling the stigma and discrimination triggered by HIV/AIDS. All over the world, the shame and stigma associated with the epidemic have silenced open discussion, both of its causes and of appropriate responses. This has caused those infected with HIV and affected by the disease to feel guilty and ashamed, unable to express their views, and fearful that they will not be taken seriously. And they have led politicians and policy-makers in numerous countries to deny that there is a problem, and that urgent action needs to be taken.

The stigma and discrimination associated with HIV/AIDS have many other effects. In particular, they have powerful psychological consequences for how people with HIV/AIDS come to see themselves, leading, in some cases, to depression, lack of self-worth and despair. Some also contemplate and commit suicide. They also undermine prevention by making people afraid to find out whether or not they are infected, for fear of the reactions of others. They cause those at risk of infection and some of those affected to continue practising unsafe sex in the belief that behaving differently would raise suspicion about their HIV-positive status. They also cause people with HIV/AIDS erroneously to be seen as some kind of 'problem', rather than part of the solution to containing and managing the epidemic.

The impact of HIV/AIDS-related stigma and discrimination does not end here. It also affects the capacity of societies to respond constructively to the devastation caused by the epidemic.

HIV/AIDS-related stigma does not arise out of the blue, nor is it something dreamed up in the minds of wicked individuals. Instead, like responses to diseases such as leprosy, cholera and polio in the past, it plays to deep-rooted social fears and anxieties. Understanding more about these issues, and the social norms they reinforce, is essential to adequately responding to HIV/AIDS-related stigma and discrimination. Otherwise, we run the risk of developing programmes and interventions that are not comprehensive, thus achieving little impact.

Global goals for HIV/AIDS cannot be met without addressing stigma and discrimination faced by people living with HIV/AIDS, young people and women and girls.

United Nations Declaration of Commitment on HIV/AIDS

'Stigma, silence, discrimination and denial, as well as lack of confidentiality, undermine prevention, care and treatment efforts and increase the impact of the epidemic on individuals, families, communities and nations' (Paragraph 13).

'By [the year] 2003, [nations should] ensure the development and implementation of multisectoral national strategies and financing plans for combating HIV/AIDS that address the epidemic in forthright terms; confront stigma, silence and denial; address gender- and age-based dimensions of the epidemic; [and] eliminate discrimination and marginalization' (Paragraph 37).

'By [the year] 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)².

HIV/AIDS in South Asia

A rapidly evolving epidemic

Almost 1 million people in Asia and the Pacific acquired HIV in 2002, bringing to an estimated 7.2 million the number of people now living with HIV in this region – a 10% increase since 2001. Current UNAIDS/WHO projections suggest that more than 40% of the estimated new infections between 2002 and 2010 will occur in Asia and the Pacific

Currently, within the region and in many South Asian countries, national HIV prevalence levels as yet remain comparatively low – majority of people in the region are not infected. This offers an important window of opportunity but is little cause for comfort. Twenty years global experience has shown that no country in the world is inherently protected by geography, culture, tradition and religion.

Moreover, in especially populous countries, low national prevalence rates can seriously distort understanding of the epidemic. India's national adult HIV prevalence rate of less than 1%, for example, offers little indication of the serious situation facing the country. In fact, an estimated 3.97 million people were living with HIV at the end of 2001. This is the second highest figure in the world, after South Africa

Elsewhere in the region, in countries such as Bangladesh, Nepal and Sri Lanka, there are rapidly developing local epidemics among those groups most vulnerable to HIV. These include sex workers, injecting drug users, men who have sex with other men, migrant populations and others made vulnerable by economic and social instability. Among injecting drug users, in particular, exceedingly high levels of infection have been reported – upwards of 50% in parts of Myanmar and Nepal, and in Manipur in India.³ High rates of needle-sharing have also been documented among drug users in Bangladesh.

If left unchecked, concentrated epidemics affecting only a few individuals can rapidly develop into more generalised ones. Globally, there is increasing infection rates among younger people and in particular among young girls. There are approximately six thousand new infections among young people everyday. Available data from Nepal and India suggest that new infections are occurring increasingly

in young people below the age of 29.⁴ This has serious implications for some countries in the Asian region in which approximately 54% of its population is below the age of 25.

Evidence from a study in India also indicates that young women who are being infected are mainly, those within the context of a monogamous relationship.⁵ NACO has estimated that of the roughly 27 million pregnancies that occur annually in India at least 100,000 occur in HIV positive women. This is likely to lead to approximately 30,000 infected babies and a further 70,000 children likely to be orphaned as a result of HIV/AIDS.⁶ In some states in India, up to 85% of women attending antenatal clinics are below 20 years of age, indicating something of where the future burden of the epidemic will lie.

Data on impact of AIDS in the region is very limited. Discrimination and stigma though have been widely reported. The NACO/UNICEF study in India on impact found that HIV/AIDS affected children are likely to be withdrawn from schools, are being forced to leave schools or prevented from playing with other children.⁷ Similar acts of discrimination were found during a situation analysis of children affected in Nepal.

In areas hard hit by the epidemic, AIDS is likely to become the leading cause of death among young adults. HIV in India is already one of the two largest and growing causes of death.⁸ Children may become the household's only breadwinners if working-age adults are sick. Exacerbated by gender stereotyping, girls are likely to be kept at home to care for sick relatives, or to do housework. This is serious enough in countries where the gender gap is slight, but in South Asia it compounds existing inequalities in the uptake of schooling by girls. Though the precise numbers of individuals as yet affected within the region is unknown, and more research is needed, there can be no room for complacency in this respect

Some key determinants of the epidemic

Structurally, South Asian countries are remarkably vulnerable to the epidemic. They have been protected so far only by the fact that the epidemic began later in this sub-region than in other parts of the world. In the majority of countries, open discussion of sex and sexuality is taboo. Many display low levels of literacy, extreme gender inequalities, high levels of sexual violence and abuse, denial of sex between men, growing levels of injecting drug use, and human trafficking.

Together with poverty and the economic inequalities that render sex work a lucrative option, these factors systematically render some groups more vulnerable than others.

Understanding this structured vulnerability is central to anticipating where the epidemic will move to next, and what might make for the basis of an effective response.

Sexual transmission is the main mode of HIV infection in all the countries of the region. Contrary to what some may wish to believe, many young people are sexually active from their mid-teenage years onwards and some even earlier. There is evidence from rural Maharashtra in India that among married adolescents, 48% of boys report having had pre-marital sex.⁹ Over 13% of 12-15 year-old boys in 15 Mumbai schools reported having had sexual experiences, over 75% with more than one partner.¹⁰ Condom use in such relationships remains the exception rather than the norm.

Young people are also prominent among injecting drug users. In India, recent data from a rapid situation assessment study on drug use shows that the age of onset of drug use in various cities ranged from 15 to 18 years.¹¹ Half of Nepal's 50,000 drug users, including non-injecting drug users, are in the age group of 16-25. Infection patterns, as in other regions, already show the disturbing trend of increased infections in young people below the age of 25.¹²

Response to the epidemic

All countries in the region have implemented national AIDS Control programmes with focus on awareness campaigns. Despite this, awareness levels remain relatively low in most countries of the region and even where awareness levels are shown to be high as in India misconceptions regarding transmission and prevention abound. Behavioural Sentinel Surveillance Data (2001) in India indicate that though overall 76% had heard of AIDS only 46.8 % in the entire country were aware of the two important methods of prevention. According to the World Bank, over 95% of 15-19 year old Bangladeshis do not know a single method of HIV prevention.

But worth noting is that consistent prevention efforts have resulted in high levels of awareness and knowledge about HIV/AIDS, and the evidence of high condom use among vulnerable populations in certain states. For example, the state of Maharashtra in India is home to a longstanding, generalized epidemic. There, HIV/AIDS responses appear to have resulted in higher levels of awareness and behavioural change among female sex workers, their clients and injecting drug users (66%, 77% and 52% of whom, respectively, said they consistently use condoms—among the highest rates in India)¹³. This may have helped prevent the state's epidemic from spinning out of control

Ignorance about the disease and lack of means of protection will condemn many to an early death. Regardless of where they live, and regardless of their age, women and men have a right to the knowledge and means by which to protect themselves and their partners against infection. It should go without saying that education has an important role to play in providing this knowledge and the skills and attitudes within which to put it into practice.

The new push for an ‘education vaccine’ is long overdue, given the power of education to fight HIV/AIDS. Indeed, no country can afford not to act. Those that are worst-affected need to turn back the spread of the epidemic and protect future generations — Uganda and Senegal, Cambodia and Thailand have shown this to be possible. Low-prevalence countries such as many of those in South Asia, on the other hand, need to recognize the speed with which complacency and denial can lead to crisis and equally, the tremendous opportunity for saving of lives and financial resources through prevention. For all countries, two mutually reinforcing objectives are paramount: namely strenuous efforts directed towards the prevention of HIV; accompanied by measures to protect and support the education system.¹⁴

Some Starting Points

“HIV/AIDS-related stigma comes from the powerful combination of shame and fear—shame because the sex or drug injecting that transmit HIV are surrounded by taboo and moral judgement, and fear because AIDS is relatively new, and considered deadly. Responding to AIDS with blame, or abuse towards people living with AIDS, simply forces the epidemic underground, creating the ideal conditions for HIV to spread. The only way of making progress against the epidemic is to replace shame with solidarity, and fear with hope.”

—Statement by Dr. Peter Piot, Executive Director, UNAIDS to Plenary of the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, Durban South Africa, 5 September 2001¹⁷

Concern about HIV/AIDS-related stigma and discrimination is not new¹⁵. It is now widely recognized that there are three phases to the AIDS epidemic in any society. The first of these is the epidemic of HIV infection. This enters a community silently and unnoticed. Next follows the epidemic of AIDS, which appears when HIV triggers life-threatening infections. Finally, there is the third epidemic—the epidemic of stigma, discrimination, blame and collective denial—that makes it so difficult to effectively tackle the first two¹⁶. HIV/AIDS-related stigmatization and discrimination make prevention difficult by forcing the epidemic out of sight and underground.

But what action is needed and what must be the priorities? Four issues are clear:

Firstly, we need clear thinking about what stigma and discrimination are, where they come from, particularly the social and cultural drivers that fuel them, and what they do.

Secondly, we need to appreciate their links to broader existing inequalities and injustices and denial of individuals' realization of human rights and fundamental freedoms.

Thirdly, we need to stimulate a better understanding of the complex stigma- and discrimination-related issues that precipitate the epidemic.

Fourthly, it is critical to set objectives for results. We need to identify opportunities for action across each and every one of the key fields identified in the UNGASS Declaration of Commitment—namely prevention; care, support and treatment; advancement of HIV/AIDS-related human rights; reduction of vulnerability; alleviation of social and economic impact, including that on children orphaned or made vulnerable by HIV/AIDS; HIV/AIDS-related research; and addressing HIV/AIDS in regions affected by conflict and disaster.

It goes without saying that our thinking and action should be rooted in the universal nature of human rights standards, principles and norms. Around the South Asia region, numerous instances of HIV/AIDS-related stigma and discrimination can be identified. Equally important is the identification of the ways in which violation of human rights and the stigma and discrimination that are bedded in these violations exacerbate the spread of HIV.

There are already many examples of the initial efforts to eliminate these forms of stigma and discrimination. Sometimes these efforts succeed and sometimes they are less successful. But wherever they occur, they are worthy of attention, not only for their potential to help us better understand the social response to HIV/AIDS, but also because they act as beacons to future success.

What Is Stigma?

“My mother-in-law has kept everything separate for me-my glass, my plate. They never discriminated like this with their son. They used to eat together with him. For me, it’s don’t do this or don’t touch that and even if I use a bucket to bathe, they yell- ‘wash it, wash it’. They really harass me. I wish nobody comes to be in my situation and I wish nobody does this to anybody. But what can I do? My parents and brother also do not want me back.”

–HIV-positive woman, aged 23, India

Stigma has ancient roots¹⁸. It has been described as a quality that ‘significantly discredits’ an individual in the eyes of others¹⁹. It also has important consequences for the way in which individuals come to see themselves.

Importantly, stigmatization is a process. The qualities to which stigma adheres (e.g. the colour of the skin, the way someone talks, the things that they do) can be quite arbitrary. Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy. Stigmatization therefore describes a process of devaluation rather than a thing.

It is also necessary, when analysing the roots and results of stigma, to demonstrate how different groups experience stigma and, most particularly, how men (especially boys) and women including girls are differentially affected by it.

Much of HIV/AIDS-related stigma builds upon and reinforces earlier negative thoughts. People with HIV/AIDS are often believed to have deserved what has happened by doing something wrong. Often these ‘wrongdoings’ are linked to sex or to illegal and socially-frowned-upon activities, such as injecting drug use. Men who become infected may be seen as homosexual, bisexual or as having had sex with prostitutes. Women with HIV/AIDS are viewed as having been ‘promiscuous’ or as having been sex workers. The family and community often perpetuate stigma and discrimination, partly through fear, partly through ignorance, and partly because it is convenient to blame those who have been affected first.

The real battle against AIDS in the region is being played out in the families and villages and towns. This sort of

discrimination is intensely personal, and it takes many forms: schoolchildren ostracizing other children on the playground, in-laws boycotting the widow of a son who has died from the disease, people being thrown out of jobs on false pretexts, families being sent away from their place of residence, hospitals and health care workers not providing any care²⁰.

Images of HIV/AIDS in the media and television, which suggest that it is a 'woman's disease', a 'junkies' disease, a disease of 'morally corrupt' people, also create HIV/AIDS-related stigma and discrimination and reinforce these stereotypes and beliefs. Although images associated with HIV/AIDS vary from country to country and place to place, they are patterned so as to ensure that HIV/AIDS-related stigma plays into, and reinforces, existing social inequalities. These include gender inequalities; inequalities that deny sex workers their dignity and rights; inequalities based on caste, class and ethnicity; and inequalities linked to sexuality in general, and homosexuality and transgendered status, in particular.

Like many other sexually transmitted infections²¹, HIV/AIDS was first perceived as a disease of 'outsiders' in the region²². In many countries in South Asia, people still believe that they are immune to the problem. In the early 1980s, for example, in India it was largely seen as problem brought in by foreigners. In the eyes of many Asian leaders, HIV/AIDS has been viewed as a disease of the West, linked to the weakness of family structures, liberal social values and moral decline.

People with HIV/AIDS are often seen not as individuals living in contexts of marginalization and inequality but as the causes of their own misfortune. This kind of approach can be seen in responses all over the region, and undoubtedly underpins indifference to the plight of some of the most heavily affected communities.

Self-stigmatization, or the shame that people living with HIV/AIDS experience when they internalize the negative responses and reactions of others, is also evident. Self-stigmatization can lead to depression, withdrawal and feelings of worthlessness. It silences and saps the strength of already-weakened individuals and communities, and causes people to blame themselves for their predicament. It has links to what

***“Life is to live fully,
not to brood”***

–Salim, HIV positive, Nepal



“It’s a tough life for victims of AIDS. They are a marginalized lot. It is not easy in a conservative society like ours. But in my case, I wanted to come out into the open. I didn’t want to hide.

–Dr. Kamalika Abeyratne, an HIV-positive physician, Sri Lanka

some writers have called ‘felt’, as opposed to enacted, stigma, in that it affects primarily an individual’s or community’s feelings and sense of pride.

It is silence, exclusion and isolation that limit our ability to provide the care and services needed by people living with HIV. It is the silence, exclusion and isolation of our leaders that prevent us from developing and marketing effective HIV prevention efforts²³.

Stigma is linked to power and domination throughout society as a whole. It plays a key role in producing and reproducing relations of power. Ultimately, stigma creates, and is reinforced by, social inequality. It has its origins deep within the structure of society as a whole, and in the norms and values that govern much of everyday life. It causes some groups to be devalued and ashamed, and others to feel that they are superior. For example, long-standing ideologies of gender have resulted in women being blamed for the transmission of sexually transmitted infections or HIV. This has influenced the ways in which families and communities react to the seropositivity of women. Many women in South Asia are blamed for the illnesses from which they and their husbands suffer despite evidence that they were recipients of the infection from their husbands.

Discrimination

Stigma is harmful, both in itself, since it can lead to feelings of shame, guilt and isolation of people living with HIV, and also because negative thoughts often lead individuals to do things, or omit to do things, that harm others or deny them services or entitlements. Hospital or prison staff, for example, may deny health services to a person living with HIV/AIDS. Or employers may terminate a worker's employment on the grounds of his or her actual or presumed HIV-positive status. Families and communities may reject and ostracise those living, or believed to be living, with HIV/AIDS. Such acts constitute discrimination based on presumed or actual HIV-positive status and violate human rights

Because of the stigma associated with HIV/AIDS, and the discrimination that may follow from this, the rights of people living with HIV/AIDS and their families are frequently violated. This violation of rights increases the negative impact of the epidemic. At the level of the individual, for example, it causes undue anxiety and distress—factors that are known in themselves to contribute to ill-health. At the level of the family and community, it causes people to feel ashamed, to conceal their links with the epidemic, and to withdraw from participation in more positive social responses. And at the level of society as a whole, discrimination against people with HIV/AIDS reinforces the mistaken belief that such action is acceptable and that those infected with HIV/AIDS should be ostracised and blamed.

Around the world, there have been numerous instances of such HIV/AIDS-related discrimination. People with (or believed to have) HIV/AIDS have been:

- Segregated in schools and hospitals, including under cruel and degrading conditions. Cases of degrading treatment have often been reported in prisons where inmates are often mandatorily confined, often without their basic needs being met, including

Discrimination occurs when a distinction is made against a person that results in their being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group.

“Being HIV positive is nobody’s fault. Society should not think they are at risk by being close to people living with HIV/AIDS. Discrimination is cruel.”

–Mohammed Nazir, HIV positive, Pakistan

access to medical care²⁴. In many parts of South Asia, despite government policies and court orders, people living with HIV are often incarcerated, kept in isolation wards or refused treatment. A study in India found that nearly one fifth of the students whose parents had HIV were forced to leave school or prevented playing with other children²⁵.

- Refused employment. There have been cases in which companies have refused employment or dismissed from work. A High Court in Mumbai, India had to step in and reinstate the dismissed workers²⁶.
- Denied the right to marry. For example, the Supreme Court in India, for some time, ruled that a person living with HIV/AIDS has no right to marry and found a family²⁷; a bill was proposed in Andhra Pradesh, India which requires mandatory HIV testing before granting marriage licenses.
- Required, when returning to their national country, to submit themselves to an HIV test. Individuals have been denied the right to return to their country on suspicion of being HIV-positive. Others have been denied visas or entry permission²⁸.
- Rejected by their communities. All over the world, people with HIV/AIDS have been banished by their communities. Throughout Central and Southern Africa and in South Asia, a woman diagnosed with HIV/AIDS may be sent back to her family or village of origin, once her serostatus becomes known²⁹. Many female sex workers have returned to Nepal after they were found to be HIV Positive.
- Killed because of their seropositive status. In India two people were killed by the public for their presumed status. A man in India killed his wife and children before attempting suicide after discovering his HIV status.

Each example above offers an illustration of individual and social stigma being acted upon and, as a result, discrimination taking place.

Human Rights

HIV/AIDS-related stigma often leads to HIV/AIDS discrimination. This, in turn, leads to the violation of the human rights of people living with HIV/AIDS, of their families and even of those presumed to be infected, such as family members or other associates.

Freedom from discrimination is a fundamental human right founded on principles of natural justice that are universal and perpetual. Human rights inhere in individuals because they are human, and they apply to all people everywhere. The principle of non-discrimination is central to the human rights thinking and practice. The core international human rights instruments prohibit discrimination based on race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status.

The United Nations Commission on Human Rights, in its resolutions³⁰, has declared that the term 'or other status' in the various international human rights instruments should be interpreted to cover health status, including HIV/AIDS. The United Nations Commission on Human Rights has further confirmed that discrimination on the basis of HIV/AIDS status (actual or presumed) is prohibited by existing human rights standards.

But why is it important to recognize the links between stigma, discrimination and human rights violations? There are several reasons:

Firstly, because stigma, discrimination and human rights violations are inter-related. They create, reinforce and legitimize each other. They form a vicious circle.

Secondly, since freedom from discrimination is a human right, there are already existing frameworks for responsibility and accountability of action. Human rights derive from the relationship between the individual and the State. They arise from the legal obligation of States to regulate the relationships between their citizens. Thus, States are responsible and accountable; not only for directly or indirectly violating rights, but also for ensuring that individuals can realize their rights as fully as possible. States have the obligation to respect, protect and fulfil human rights.

In relation to discrimination, the obligation to respect requires States not to directly or indirectly discriminate in law, policy or practice. The obligation to protect requires

Discrimination against people living with HIV/AIDS, or those thought to be infected, is a clear violation of their human rights.

States to take measures that prevent third parties from discriminating³¹, and the obligation to fulfil requires States to adopt appropriate legislative, budgetary, judicial and other measures to ensure that strategies, policies and programmes are developed to address the discrimination and to ensure redress to those who have been discriminated against. The existence of HIV/AIDS-related discrimination is a litmus test for the lack of respect, protection and fulfilment of human rights.

A human rights framework provides avenues for people who suffer discrimination on the basis of their actual or presumed HIV-positive status to have recourse through procedural, institutional and monitoring mechanisms. Since HIV/AIDS-related discrimination constitutes a violation of human rights, persons who discriminate are accountable by law and redress can be provided, where appropriate.

Procedural, institutional and other monitoring mechanisms exist to ensure accountability at national, regional and international levels. At national level, these include courts of law, national human rights commissions, ombudsmen, law commissions and other administrative tribunals. For example, the National Human Rights Commission of India has undertaken various activities to promote and protect HIV/AIDS-related rights.

Beyond legal redress, there are many other ways of tackling HIV/AIDS-related stigma and discrimination. Public information campaigns, for example, have an important role to play in helping people understand the unfairness and unjustness of stigmatization and discrimination. They can also change individual and social attitudes. Participatory education can help individuals place themselves in the position of someone who has suffered discrimination and thereby appreciate the injustice of discriminatory actions. Through grass-roots activism, advocacy and involvement in the development and implementation of policy, the actions of people living with and affected by HIV/AIDS can be a radical force for change, breaking down the barriers to the full realization of human rights.

In South Asia, a network of editors have issued a statement for responsible reporting about HIV. In Sri Lanka, the media has for long created an environment for non-stigmatisation and discrimination of people living with HIV/AIDS. On television, the Sri Lankan Cricket Captain and UNAIDS Ambassador Sanath Jaysuria, calls for an end to stigma and discrimination. Various documentaries and films on HIV/AIDS in India have focussed on stigma and discrimination faced by people living with HIV/AIDS. A study showed that this led to greater acceptance of people living with HIV/AIDS. It is important to ensure that all forms of discrimination that fuel the epidemic are equally addressed and action taken.

Tackling discrimination

With respect to measures to counter discrimination, a more programmatic approach has frequently been adopted. This has involved a variety of actors coming together to counter the negative consequences of HIV/AIDS-related stigma as it impacts upon lives and communities.

In India, for example, the Lawyers' Collective in Mumbai has successfully defended workers who have been discriminated against and lost their jobs on account of their HIV-positive status. The Collective has also raised public awareness about HIV/AIDS through public rallies and mobilizes public opinion against stigma and discrimination. One of its most significant achievements to date has been the upholding of the 'suppression of identity' clause. This allows a person with HIV/AIDS to file his or her case under a pseudonym³².

In India, work is under way in New Delhi to establish HIV-patient-friendly hospitals. The goal is to make services more attuned to the needs of people with HIV/AIDS. Among the measures being taken is policy development on matters such as pre- and post-test counselling, confidentiality and the importance of informed consent. Efforts are also being made to extend staff education and training, and to strengthen the application of universal precautions in patient care³³.

Lack of access to antiretroviral treatment is a key issue that enhances or advances HIV/AIDS-related stigma and discrimination in many countries. In South Asia, most people cannot afford the costs of treatment. The perceived 'untreatability' of AIDS is a key factor contributing to the stigmatization of many of those affected. Even where treatment is available, it is likely that women, girls and young people will have limited access to them. As long as HIV/AIDS continues to be equated with serious illness and death, public attitudes towards the epidemic seem likely to be slow to change. For this reason, as well as on grounds of equity and justice, efforts have to be made to extend the availability of antiretroviral drugs.

What could be some successful approaches?

Continuing advocacy is needed for social change in response to HIV/AIDS-related stigmatization and discrimination. The role of people with HIV/AIDS and of religious and political leaders in such a process cannot be underestimated. In Bangladesh, Imams have started to address issues of HIV/AIDS and acceptance of people affected with HIV as part of the Friday sermons. Senior Parliamentarians from South Asia are now taking an increased interest in rights of people affected by HIV/AIDS.

Empowerment of people living with, and affected by HIV/AIDS is imperative. Community mobilization, advocacy and social change must take place alongside interventions to change the broader context in which individuals and communities live³⁴. Local 'ownership' of HIV/AIDS, such as that fostered as part of building an AIDS-competent community³⁵, is essential to a successful response.

Action is needed to tackle the gender, racial and sexual inequalities and stereotypes upon which HIV/AIDS-related stigma and discrimination so often feed. In particular, efforts should be made to counter prejudice and misunderstanding and to protect the human rights of sex workers, men who have sex with men and other minorities who are discriminated against.

Promote life-skills education and counselling to help HIV-infected and -affected children cope with stigma.

Ensure that comprehensive care and services, including voluntary counselling and testing (VCT), and follow-up care are available to enable individuals to learn their serostatus and provide support to enable them disclose their status to other family members.

Raise awareness so that families and communities can access interventions (e.g., prevention of mother-to-child transmission, care and support services, etc.) as they become available, or hold authorities accountable if such services are not available.

Legal protection for people living with HIV and AIDS is a powerful way of redressing, and thereby mitigating, the unequal power relations, the social inequality and the exclusion that lie at the heart of HIV/AIDS-related stigmatization and discrimination.

Such protection should be promoted, together with appropriate reporting and enforcement mechanisms. Redressal against stigma and discrimination in the region has often come through legal action and judicial pronouncements.

Greater support is needed for community legal aid centres and/or legal services to tackle instances of discrimination and the abuse of human rights. Basing such services in existing AIDS service organizations, or organizations of people living with HIV/AIDS, may be one way of helping develop trust among those who have experienced discrimination, especially where such organizations are already valued and respected by the community.

Training and support for existing legal aid institutions in developing their approach to human rights and HIV/AIDS are needed, alongside the creation of lawyers' collectives specializing in HIV/AIDS-related concerns³⁶. Training and supporting members of associations of people living with HIV/AIDS are also important, so that these associations can provide in-house paralegal counselling and advice.

The workplace provides an excellent opportunity to set standards that protect human rights and to establish a supportive environment for those living with HIV and AIDS. The ILO Code of Practice on HIV/AIDS and the World of Work provides basic principles to guide policy development, as well as guidelines for practical programming. A workplace policy on HIV/AIDS is a powerful instrument with which to combat discrimination and encourage solidarity through education and awareness-raising³⁷.

Within the health-care setting, ensure that codes of ethics and professional conduct for health-care services are in place and are enforced, and that their application to HIV/AIDS is taught within professional training curricula. Offer sufficient forms of redress should violations of professional ethics occur.

Encourage practical HIV-related training for all health-care workers to promote better understanding, to promote confidentiality and to reduce unfounded anxiety. The use of universal precautions will not only allay staff anxieties but will also help protect the identities and rights of infected patients.

Concrete action needs to be taken to ensure greater access to, and uptake of, treatment drugs. Helping people to understand that it is possible to live with HIV/AIDS, and to recognize that treatment advance promises real hope for the future, is an important step in dissipating fear and anxiety about the epidemic in the workplace and in the community. Ensure that HIV/AIDS-related subjects, including counselling skills, are included in the pre- and in-service training of religious leaders.

The 2002-2003 World AIDS Campaign on Stigma and Discrimination

The 2002–2003 World AIDS Campaign will encourage leaders at all levels, and in all walks of life, to visibly challenge HIV-related discrimination, spearhead public action and act against the many other forms of discrimination that people face in relation to HIV/AIDS. Also key is the active involvement of people living with HIV/AIDS in the response to the epidemic, and in ensuring that prevention, treatment and support services are accessible to all.

In 2002, the campaign targeted individuals. The objective was for each person to understand how their actions contribute to stigma and discrimination. In 2003, the campaign will focus on the role of institutions in reinforcing stigma and discrimination and how these can be overcome. This second phase of the campaign will focus on institutional reform and responses. This will include looking at the issue of stigma and discrimination from the human rights and legal perspectives. It will advocate institutional reform across different sectors. At the political level, it will focus on advocating policy law reform, as necessary, and increasing efforts towards the enforcement of legal rights. At the implementation level, it will address ways in which existing interventions can be strengthened and expanded, and new interventions can be planned and implemented to help reduce stigma and discrimination and resulting human rights violations.

Live... and Let Live

With its focus on stigma and discrimination, the 2002–2003 World AIDS Campaign is aimed at helping prevent, reduce or eliminate stigma and discrimination by supporting effective international, regional and national strategies. The Campaign will also tackle wider existing social inequalities—especially those of gender, sexual orientation and race—hence its slogan ‘Live and Let Live’.

Live and let live was chosen as the slogan because:

- it addresses the personal empowerment of PLWHA and their families, as well as those particularly vulnerable to infection, to be able to see a better future;
- it sends a positive signal that underscores the importance of people living their lives to the fullest;
- it emphasizes a powerful will to live, despite HIV/AIDS;
- it sends a clear message to governments, organizations and institutions concerning their obligations to ensure the right to life, the right to the highest attainable standard of health and the quality of life of those affected by/infected with HIV;
- it has strong linkages to the human rights framework;
- it challenges people to think about how their thoughts and actions can affect communities and individuals living with HIV/AIDS;
- it is a call for a more caring and understanding world for those affected by/infected with HIV.
- it promotes the acceptance of people for who they are;
- it seeks to boost prevention efforts and investment in care and treatment for HIV/AIDS; and
- it is relevant for all cultures, all genders and all age groups, as well as differing socioeconomic contexts.

Help us fight fear, shame, ignorance and injustice worldwide.

Examples of positive action in South Asia

Combating Stigma and discrimination as part of the National Strategic framework for AIDS prevention and care

Bangladesh's new strategic plan recognises the need to eliminate stigma and discrimination in its goal statement³⁸. Elsewhere in the region, most national strategic plans have included activities aimed at decreasing stigma and discrimination.

In India, the National AIDS Control Organisation has issued several guidelines to ensure that stigma and discrimination is not allowed to take place. A circular was sent by the Ministry of Health in Sri Lanka to all hospitals asking them not to discriminate against people living with HIV/AIDS. Guidelines were also issued by them to ensure that burial procedures respect the dead.

In Pakistan, the right to health is recognised in Article 38 of the constitution. Various AIDS programmes are based on the principle of greater involvement of People Living with HIV/AIDS. Various programmes have been initiated to empower those affected. Several NGOs are providing support to people living with HIV/AIDS.

The active role of the judiciary

In India, the Supreme Court has reinstated the 'right to marry' for people living with HIV/AIDS after initially suspending them. The Indian courts have also allowed People living with HIV/AIDS to file cases under pseudonyms to protect their identity. The courts have freed people who have been jailed for being HIV Positive. The courts in Bangladesh have passed various judgments protecting the rights of sex workers.

Several Legal aid groups such as the Lawyer's Collective in collaboration with NGOs have brought Public Interest Litigations to Indian courts to bring about change in national policies and accelerate the national response.

People living with HIV- taking the lead

The Indian Network of Positive people has been advocating for rights of people living with HIV/AIDS. They are part of the UN Themegroup on HIV/AIDS and various other national and state committees. Nepal and Sri Lanka too have formed National networks of positive people. Similar efforts are also on in Bangladesh. Many people living with HIV/AIDS in the region play an active role in advocacy and other prevention and care efforts.

In Nepal, Prerana, a support group of People Living with HIV/AIDS is engaged in peer support, advocating for the HIV/AIDS issues and facilitating access to quality treatment. Several NGOs provide support to migrant and trafficked women at transit points while re-entry and departure.

Decreasing Stigma and discrimination through public campaigns

In Sri Lanka, public service campaigns to educate the public, sensitisation workshops with the judiciary, the establishment of a HIV/AIDS ethic committee, have set the foundations for work in this area.

Various celebrities in India, Nepal, Bangladesh and Pakistan lent their services in various public information efforts by appearing in TV and radio spots, posters and other public events.

In Bangladesh, a commercially produced film based on HIV/AIDS as the theme, ran to packed audiences and highlighted the role played by stigma and discrimination.

Role of the faith based organisations in reducing stigma and discrimination

In several parts of Bangladesh and India, Imams are addressing the issue of stigma and discrimination after the Friday prayers. Various church groups in India have started to talk to their community members about HIV/AIDS and in many countries of the region they provide care and prevention services to those affected.

Conclusion

If effective responses to HIV/AIDS-related stigma and discrimination are to be promoted in the region, work has to occur simultaneously on several fronts:

- ▶ communication and education to encourage better understanding among the general public and different sectors.
- ▶ action and intervention to establish a more equitable policy context.
- ▶ legal challenge, where necessary, to bring to account governments, employers, institutions and individuals.
- ▶ creation of an enabling environment in which people living with HIV/AIDS and their families, women, boys and girls are able to access prevention and care services.
- ▶ Access to quality and comprehensive care.

The fundamental objective, however, is to strive for action based on this understanding—action that will promote egalitarian and gender-progressive role models, and that will help guide the manner in which we interact with one another.

Endnotes

- ¹ Also see issue papers: "Vulnerability and opportunity: HIV/AIDS, Gender and Violence against Women in South Asia" and "Education and HIV/AIDS" prepared for the South Asia High Level Conference: Accelerating the Momentum in the Fight Against AIDS in South Asia.
- ² http://www.unaids.org/whatsnew/others/un_special/Declaration2706_en.htm
- ³ http://www.unaids.org/hivaidsinfo/statistics/fact_sheets/pdfs/India_en.pdf
- ⁴ NACO (2001) Estimation of HIV/AIDS in India. <http://www.naco.nic.in/indianscene/esthiv.htm> and NACO (2000) Combating HIV/AIDS in India. <http://www.naco.nic.in/indianscene/country.htm> See also http://www.unaids.org/hivaidsinfo/statistics/fact_sheets/pdfs/India_en.pdf and http://www.unaids.org/hivaidsinfo/statistics/fact_sheets/pdfs/Nepal_en.pdf
- ⁵ UNAIDS and Sociometric Corporation (2001) *Gender Almanac*. <http://www.unaids.org/gender/docs/Gender%20Package/GenderandAIDSAlmanac.pdf>
- ⁶ *Feasibility study of administering short AZT interventions among HIV infected mothers to prevent MTCT:MOHFW, NACO, UNICEF, Dec.2001*
- ⁷ Ravi K Verma, et al. The impact of HIV/AIDS related deaths on households and their coping strategies: A study with special reference to children: A case of India. A UNICEF-NACO supported study,2000
- ⁸ National AIDS Control Organisation , 2001
- ⁹ KEM Hospital Research Centre. (1997) *Adolescent Sexuality and Fertility: A survey in rural Maharashtra*. Pune, KEM Hospital Research Centre
- ¹⁰ Abraham, L. (1998) *Understanding Youth Sexuality: A study of college students in Mumbai*. Mumbai, TISS.
- ¹¹ Gary Reid & Genevieve Costigan' Revisiting the Hidden Epidemic' A situation Assessment of Drug use in Asia in the context of HIV/AIDS. The Centre for Harm Reduction, the Burnet institute, January 2002
- ¹² National AIDS and STD Control Centre, Kathmandu. 2001
- ¹³ National Baseline General Population Behavioural Surveillance Survey, 2001. NACO, MOHFW, GOI
- ¹⁴ Bundy, D. (2002) UNAIDS IATT on Education Press Release. October 22nd
- ¹⁵ As far back as 1985, the author and activist Cindy Patton was writing about HIV/AIDS-related stigma and discrimination in *Sex and Germs: The Politics of AIDS*. Here, she pointed to their links to fear of germs and disease, to fear of death, and to deep-seated worries about sex and sexuality. A couple of years later, Susan Sontag addressed similar concerns in *AIDS and its Metaphors*, highlighting parallels between the social response to HIV/AIDS and earlier societal anxieties about leprosy, tuberculosis and cancer.
- ¹⁶ Mann J (1987) Statement at an informal briefing on AIDS to the 42nd Session of the United Nations General Assembly, New York, 20 October.
- ¹⁷ <http://www.unaids.org/whatsnew/speeches/eng/piot040901racism.htm>
- ¹⁸ The origins of the word can be traced to classical Greece where outcast groups were branded, or physically marked, as a permanent measure of their status.
- ¹⁹ Drawing on his research with individuals who had experienced stigmatization, including people with mental illness, physical deformities or socially 'deviant' behaviours, the US sociologist Erving Goffman has argued that the stigmatized individual is a person with a 'spoiled identity' who is 'rendered unworthy' in the eyes of others.
- ²⁰ <http://www.yaids.org/network/otrs/vol1iss4.htm>
- ²¹ Most notably, syphilis in 15th and 16th century Europe
- ²² Gilman S (1988) *Disease and Representation: Images of illness from madness to AIDS*. New York, Cornell University Press.
- ²³ <http://www.nrharural.org/pagefile/aidsbook.html>
- ²⁴ See <http://www.prisoners.org/hivin.htm> and <http://www.aidslaw.ca/Maincontent/issues/prisoners.htm> and <http://www.unaids.org/publications/documents/sectors/prisoners/prisoners.html>
- ²⁵ Impact of HIV/AIDS related death and morbidities on Households and their coping strategies, NACO-UNICEF
- ²⁶ HIV / AIDS related, stigma and discrimination, a review and suggested ways forward for South Asia, October 2002, UNAIDS
- ²⁷ Judgement given by the Supreme Court in *Mr X vs. Hospital Y Authority* [reported in (1998) 8 SCC 296]. Considering that, at present, there is no cure for AIDS, in effect the decision in *Mr X* implies that the Petitioner's fundamental right to marry was completely infringed, and he could never marry. This judgement has now been set aside by the Supreme
- ²⁸ See <http://travel.state.gov/HIVtestingreqs.html> for a list developed by the US Department of State that highlights about 60 countries that require HIV tests, and conditions that are applied; see also Carlier J-Y, *The free movement of persons living with HIV/AIDS*, EU HIV/AIDS Programme in Developing Countries, European Commission, Luxembourg, 1999; Deutsche AIDS Hilfe and AIDS Info Docu Schweiz, Quick Reference, Travel and residence regulations for people with HIV and AIDS, Third edition. Berlin, December 2001. The text is accessible at www.aidsnet.ch/immigration/d (German) and at www.aidsnet.ch/immigration/f (French); Swiss Federal Department of Foreign Affairs (<http://www.hivnet.ch>) and <http://travel.state.gov/HIVtestingreqs.html>
- ²⁹ See http://www.panos.org.uk/aids/stigma_countries_study.htm and also UNAIDS (2000) *HIV and AIDS-related stigmatization, discrimination and denial: forms, contexts and determinants. Research studies from Uganda and India*. Geneva, UNAIDS.
- ³⁰ United Nations Commission on Human Rights, Resolutions 1999/49, 2001/51, 2002/47.
- ³¹ For example, the adoption of legislation to ensure equal access to health care and health-related services provided by third parties, to control the marketing of medicines and medical equipment, and to ensure that medical practitioners and other health professionals meet appropriate standards of education, skill and ethical codes of conduct.
- ³² <http://www.hri.ca/partners/lc/about/cases.shtml>
- ³³ <http://www.popcouncil.org/horizons/projects.html>
- ³⁴ Sweat M, Dennison J (1995) Reducing HIV Incidence in Developing Countries with Structural and Environmental Interventions, *AIDS* 9, Suppl. A, S225-257, and Parker R, Easton D, Klein C (2000) Structural Barriers and Facilitators in HIV Prevention: A Review of International Research. *AIDS*, 14, Suppl. 1, S22-S32.
- ³⁵ <http://www.unaids.org/bestpractice/digest/files/thepromotionofcommunity.html>
- ³⁶ For example: *Alter Law* in the Philippines and the *Lawyers Collective HIV/AIDS Unit* in Mumbai, India. These are groups of lawyers specializing in HIV/AIDS-related cases and offering free legal service in this area.
- ³⁷ The ILO Code of Practice on HIV/AIDS and the World of Work is being used in a number of countries as the basis for the revision of employment laws and other instruments in order to establish the rights of, and guide conduct towards, workers living with HIV or AIDS.
- ³⁸ The goal of the Bangladesh HIV/AIDS programme is to control the spread of HIV infection within high-risk groups and to limit its spread to the general population, without discriminating and stigmatising the high risk groups.