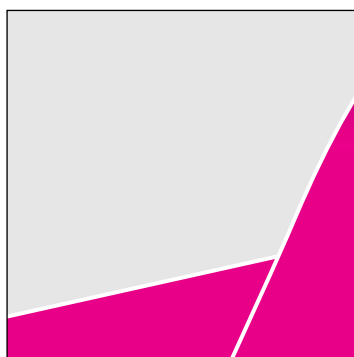


REVISED

World AIDS Campaign 2002–2003

A conceptual framework and basis for action:

HIV/AIDS
stigma and discrimination



Joint United Nations Programme on HIV/AIDS

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I. BACKGROUND AND RATIONALE

The World AIDS Campaign for the years 2002–2003 will focus on stigma, discrimination and human rights. The main objective of the campaign is to prevent, reduce and ultimately eliminate HIV/AIDS-related stigma and discrimination, wherever it occurs and in all its forms.

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.

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 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. They also undermine prevention by making people afraid to find out whether or not they are infected, and seek treatment, 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. And they 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. In some countries, though, the picture is beginning to change. The greater availability of antiretroviral treatment can begin to shift deep-seated prejudices and attitudes, as such availability encourages HIV/AIDS to be seen as a long-term manageable condition, enabling individuals to be more open about their serostatus if access to treatment is sustained and guaranteed.

In countries all over the world, there are well-documented cases of people with HIV/AIDS being stigmatized, discriminated against and denied access to services on the grounds of their serostatus¹. At work, in education, in health care and in the community, people may lack the education to understand that HIV/AIDS cannot be transmitted through everyday contact, and they may not know that infection can be avoided by the adoption of relatively simple precautions. This lack of awareness can lead people to stigmatize and discriminate against those infected, or presumed to be infected, with HIV/AIDS. Gender-based stigma and discrimination require special mention. The power relations that underscore gender

¹ See, for example, the recent report by Panos: http://www.panos.org.uk/aids/stigma_countries_study.htm
But see also UNAIDS (2000) *HIV and AIDS-related Stigmatization, Discrimination and Denial: Forms, Contexts and Determinants. Research studies from Uganda and India*. Geneva, UNAIDS.

I. BACKGROUND

relations and that tightly intersect with discrimination against women mean that women are unable to say “No” to unwanted or unprotected sex. This provides highly combustible fuel for 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. Despite the catastrophe, silence prevails and action is slowed because of stigma and denial and, ultimately, because of people’s fears about being open. In 1999, for example, an estimated 860 000 children lost their teachers to AIDS in sub-Saharan Africa. In Zambia, teacher deaths caused by AIDS are equivalent to about half the total number of new teachers the country manages to train annually². A similar situation prevails among many other groups of government workers. This catastrophe calls for more to be done. Part of the response lies in addressing the existing widespread stigma and discrimination.

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)³.

HIV/AIDS-related stigma does not arise out of the blue, nor is it something dreamed up in the minds of 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

² http://www.unaids.org/worldaidsday/2001/Epiupdate2001/EPIupdate2001_en.doc

³ http://www.unaids.org/whatsnew/others/un_special/Declaration2706_en.htm

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.

II. SOME STARTING POINTS

Concern about HIV/AIDS-related stigma and discrimination is not new⁴. 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 two⁵. HIV/AIDS-related stigmatization and discrimination make prevention and treatment difficult by forcing the epidemic out of sight and underground.

“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 Peter Piot to Plenary of the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, Durban South Africa, 5 September 2001⁶

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 focus the World AIDS Campaign to stimulate a better understanding of the how stigma and discrimination fuel the epidemic, and the role that greater access to treatment could have in reducing prejudice against people living with HIV/AIDS and associated denial of their entitlement to human rights.

⁴ 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 few 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.

⁵ Mann J (1987) Statement at an informal briefing on AIDS to the 42nd Session of the United Nations General Assembly, New York, 20 October.

⁶ <http://www.unaids.org/whatsnew/speeches/eng/piot040901racism.htm>

III. WHAT IS STIGMA?

- Fourthly, it is critical to set clear 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 world, 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 embedded 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.

III. WHAT IS STIGMA?

Stigma has ancient roots⁷. It has been described as a quality that ‘significantly discredits’ an individual in the eyes of others⁸. 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.

Much 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.

⁷ 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.

⁸ 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.

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

The real battle against AIDS in Africa is being played out in the families and villages of Africa, where the authority of government rarely extends. This sort of discrimination is intensely personal, and it takes many forms: schoolchildren ostracizing other children on the playground, or in-laws boycotting the widow of a son who has died from the disease⁹.

Images of HIV/AIDS in the media and television, which suggest that it is a ‘woman’s disease’, a ‘junkies’ disease, a ‘Black disease’, an ‘American disease’ or a ‘gay plague’, also create HIV/AIDS-related stigma and discrimination and reinforce these stereotypes and beliefs. Although images associated with HIV/AIDS vary, 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 race and ethnicity; and inequalities linked to sexuality in general, and homosexuality and transgendered status, in particular.

Like many other sexually transmitted infections¹⁰, HIV/AIDS was first perceived as a disease of ‘outsiders’¹¹. In the early 1980s, for example, and among gay and other homosexually active men in Europe and Australia, it was seen as being closely linked with the United States of America. In the eyes of some African and 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. With the passage of time, and for diverse reasons, in most countries of the world, AIDS has come to be associated with sub-Saharan Africa.

Racism and xenophobia are evident, not only with respect to the presumed ‘origins’ of HIV/AIDS, but also with respect to the stigmatization and discrimination that have followed in the wake of the epidemic. The racist assumptions of many early AIDS-related discourses were clear in startling statements about ‘African sexuality’ that were typical during the early years of the epidemic¹².

But xenophobia and racism have not only shaped dominant images and cultural constructions of the epidemic, they have also been reproduced within it. Thus, people with HIV/AIDS from racial and ethnic minorities 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 world, and undoubtedly underpins indifference to the plight of some of the most heavily affected communities.

⁹ <http://www.yaids.org/network/otrs/vol1iss4.htm>

¹⁰ Most notably, syphilis in 15th and 16th century Europe

¹¹ Gilman S (1988) *Disease and Representation: Images of illness from madness to AIDS*. New York, Cornell University Press.

¹² These often evoked images of sex between humans and animals, or of exotic cultural practices such as the eating of raw or inadequately cooked green monkey flesh.

IV. DISCRIMINATION

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 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 efforts¹³.

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 are blamed for the illnesses from which they and their husbands suffer.

IV. 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 ostracize 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.

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

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

¹³ <http://www.nrharural.org/pagefile/aidsbook.html>

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 ostracized 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 access to medical care¹⁴;
- refused employment. The case of *Hoffmann vs South African Airways (SAA)* was an appeal from the Witwatersrand High Court concerning the constitutionality of South African Airways' practice of not employing people living with HIV as cabin attendants. In the High Court, SAA defended its policy as promoting the safety and health of its passengers and its own competitive capacity. The High Court upheld SAA's defence. Fortunately, the Constitutional Court of South Africa set aside the decision of the High Court and held that SAA had infringed Mr Hoffmann's constitutional right not to be unfairly discriminated against. The court further held that people living with HIV have been stigmatized and, as one of the most disadvantaged groups in society, deserve special protection from the law¹⁵;
- denied the right to marry. For example, the Supreme Court in India ruled that a person living with HIV/AIDS has no right to marry and found a family¹⁶; Further, some jurisdictions require mandatory HIV testing before granting marriage licenses;
- required, when returning to their national country, to submit themselves to a 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 permission¹⁷;
- 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 known¹⁸; and

¹⁴ See <http://www.prisons.org/hivin.htm> and <http://www.aidslaw.ca/Maincontent/issues/prisons.htm> and <http://www.unaids.org/publications/documents/sectors/prisons/prisons.html>

¹⁵ *Hoffmann v South African Airways (SAA)*, 2001 (1) SA 1 CC. A settlement offer was made by South African Airlines, and the matter was dealt with out of court. The offer included SAA unconditionally admitting that the exclusion of Mr 'A' based on his HIV-positive status was unjustified and that SAA would pay Mr 'A' the sum of 100 000 South African Rand as compensation and redress. Additionally, SAA would pay all legal costs. See also <http://www.hri.ca/partners/alp/press/press1.shtml>

¹⁶ 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.

¹⁷ 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>

¹⁸ 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.

- killed because of their seropositive status. In December 1998, a young community volunteer, Ms Gugu Dlamini, was stoned and beaten to death by neighbours in her township near Durban, South Africa after she had spoken out openly on World AIDS Day about her HIV infection.

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

V. HUMAN RIGHTS

As noted, 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 resolutions¹⁹, 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.

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

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.

¹⁹ United Nations Commission on Human Rights, Resolutions 1999/49, 2001/51, 2002/31.

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 States to take measures that prevent third parties from discriminating²⁰, 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 Commissions of South Africa, Ghana and India and the Ombudsman of Costa Rica have undertaken various activities to promote and protect HIV/AIDS-related rights in their countries.

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.

It is important, during and beyond this campaign, to ensure that all forms of discrimination that fuel the epidemic are equally addressed and action taken. The campaign must move beyond the documentation or flagging of the issue to creating positive role models and encouraging positive action.

VI. KEY STAKEHOLDERS

As tools for tackling HIV/AIDS-related stigma and discrimination, policy and legal reform will have a limited impact unless supported by the values and expectations of a society as a whole. Widespread and enduring changes in social attitudes are required if we are to make headway against HIV/AIDS-related stigma and discrimination.

²⁰ 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.

Bringing about such change requires mobilizing many different stakeholders, including people living with and affected by HIV/AIDS; partners, friends and families; religious and traditional leaders; legal and civil rights groups; nongovernmental and community-based organizations; the business community and workers' organizations; doctors, politicians, nurses and health-care workers; teachers, youth leaders, women leaders and community workers; and the police and the military. Additionally, links need to be made with broader struggles that address underlying economic, social, cultural and political inequalities—for example, gender inequality, the rights of the child, the rights of minorities, and the rights of refugees and other people displaced as a result of persecution or violent conflict.

Central to this effort must be action to transform social attitudes and values. Given the fact that the roots of much HIV/AIDS-related stigma and discrimination lie in existing injustices and inequalities, in order to tackle such stigma and discrimination, these injustices and inequalities must be addressed. But how can this be achieved?

VII. SUCCESSFUL ACTIONS AND RESPONSES

Documented efforts to challenge HIV/AIDS-related stigma and discrimination remain relatively rare. Research is urgently needed to identify the most effective ways of tackling stigma and discrimination across a range of contexts. Also needed are examples of programmatic success. What follows is a stocktaking of selected successful actions and responses. Further case studies will be made available throughout the course of the World AIDS Campaign.

Countering stigma

While a recent review²¹ concluded that 'relatively few interventions to reduce AIDS stigma have been conducted (or at least rigorously evaluated, documented and published) in developing countries', research undertaken also indicates that local communities have been exploring ways of reducing levels of stigma through:

- the dissemination of information;
- coping-skills acquisition;
- counselling approaches;
- programmes promoting greater involvement with people living with HIV/AIDS; and
- monitoring violations of human rights and creating a supportive legal environment to enable people to challenge discrimination.

In **Israel**²² and in **Jamaica**²³, more positive attitudes towards people living with HIV/AIDS have been promoted through peer education, lectures, pamphlets or workshops, although the effects of such behavioural change remain undocumented.

²¹ See <http://www.popcouncil.org/pdfs/horizons/litrwstigidisc.pdf>. The discussion of stigma-reduction measures that follows draws heavily upon this review.

²² Soskolne V et al. (1993) Immigrants from a Developing Country in a Western Society. Evaluation of a HIV Education Programme. Paper presented at the International Conference on AIDS, Berlin.

²³ Hue L, Kauffman C (1998) Creating Positive Attitudes towards Persons Living with HIV/AIDS among Young People in Hostile Environments. Paper presented at the International Conference on AIDS, Geneva.

Combining information-based approaches with counselling has been shown to increase disclosure among people living with HIV/AIDS, and has triggered improved community attitudes compared with baseline measures in countries such as **Uganda**²⁴ and **Zimbabwe**²⁵. In Uganda, the work of The AIDS Support Organisation (TASO) and other community-based groups has been central to encouraging greater openness about the epidemic and in providing support and care to individuals, families and communities living with HIV/AIDS²⁶.

Zambia was one of the first African countries to implement HIV home-care services, and the Ndola Catholic Diocese Home-Based Care Programme has been internationally recognized for the high quality of its work. Thanks to strong community participation and the motivation of the programme's volunteers, over 70% of those in need of HIV/AIDS-related care are being reached²⁷. Consequently, perhaps, negative attitudes towards HIV/AIDS reportedly lessened and local people have been empowered with the knowledge, skills and self-confidence they need to cope with the impact of the epidemic²⁸.

In Phayao Province in the north-east of **Thailand**, multisectoral work bringing together a range of governmental and nongovernmental organizations was key to reducing new infections in this badly-affected area in the late 1990s, and in promoting good-quality home- and community-based care. A people-oriented approach facilitated greater openness about the epidemic, and the promotion of a 'care not scare' approach reportedly stimulated greater social cohesion and support²⁹.

In the **United Republic of Tanzania**, teachers and health workers implemented a two-to-three-month programme of AIDS-related information, small group discussions, and role-play to improve primary-school-age children's knowledge, attitudes and practices. Follow-up 12 months later showed that attitudes towards people living with HIV/AIDS had significantly improved³⁰.

In the **United States of America**, an early study used information and coping-skills development to resolve negative feelings among physical therapy students and increase their willingness to treat people living with HIV/AIDS³¹.

Contact with HIV-infected or -affected groups has been used in several studies and programmes. The belief here is that a more personal relationship with people living with HIV/AIDS (either through face-to-face conversations or by hearing a testimonial from infected or affected individuals) will demystify and dispel misinformation, generating empathy, which, in turn, reduces stigma and prejudice. Such work shows mixed results, with some studies reporting reductions in negative attitudes, and others not.

²⁴ Kaleeba N et al. (1997) Participatory Evaluation of Counselling, Medical and Social Services on The AIDS Support Organisation (TASO). *AIDS Care*, 9, 13-26.

²⁵ Kerry K, Margie C (1996) Cost-Effective AIDS Awareness Program on Commercial Farms in Zimbabwe. Paper presented at the International Conference on HIV/AIDS, Vancouver.

²⁶ Kaleeba N et al. (2000) *Open Secret: People facing up to HIV and AIDS in Uganda*. St Albans, TALC.

²⁷ Nsutebu E et al. (2001) 'Scaling up HIV/AIDS and TB home-based care: lessons from Zambia', *Health Policy and Planning*, 16. Summary at <http://www.id21.org/health/h5en1g1.html>

²⁸ <http://www.unaids.org/bestpractice/digest/files/Volunteersinhomocare.html>

²⁹ <http://www.unaids.org/publications/documents/care/general/una0004e.pdf>

³⁰ Klepp K et al. (1997) AIDS Education in Tanzania: Promoting risk reduction among primary school children. *American Journal of Public Health*, 87, 1931-1936.

³¹ Held S (1992) The Effects of an AIDS Education Program on the Knowledge and Attitudes of a Physical Therapy Class. *Physical Therapy*, 73, 156-164.

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 **Thailand**, the Thai Business Coalition, which comprises around 125 businesses, including multinational companies, has developed training courses and a manual to support good workplace policy and practice. Documented effects of this work include HIV-positive employees reporting increased levels of acceptance and support, human resources personnel requesting technical assistance in the development of non-discriminatory policies, and staff volunteering to participate in the work of HIV/AIDS NGOs and/or specific HIV/AIDS projects³³.

The Brazilian subsidiary of Unilever has reinforced the company's internationally adopted HIV/AIDS response with an HIV/AIDS programme focused not just on employees, but also on their families and the community. The company used one of its brands—the AXE deodorant—to identify a campaign promoting greater awareness and acceptance among 14–25-year-old men. The company subsequently used the platform of the Brazilian Business Council for HIV/AIDS to share their experience and materials with other companies³⁴.

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 care³⁵.

In **South Africa**, the Centre for the Study of AIDS at the University of Pretoria has been active in challenging racist and prejudiced attitudes among staff and students. The Centre has also introduced HIV/AIDS-related concerns into elements of the higher education curriculum, including in subjects such as law, agriculture and engineering. This has led to greater understanding of the issues within the university context, de-stigmatizing and enhancing discussion of HIV/AIDS-related concerns³⁶.

³² <http://www.hri.ca/partners/lc/about/cases.shtml>

³³ UNAIDS (1997) *The Business Response to HIV/AIDS. Innovation and Partnership*. Geneva, UNAIDS.

³⁴ http://www.businessfightsaids.org/webfiles/html/awards_prewin.html

³⁵ <http://www.popcouncil.org/horizons/projects.html>

³⁶ <http://www.csa.za.org/>

Also in **South Africa**, the AIDS Law Project at the University of Witwatersrand has done much to raise public awareness of HIV/AIDS-related stigma and inequalities. It has challenged HIV/AIDS-related discrimination in the highest-level courts, on issues such as unfair dismissal and discrimination in prisons³⁷.

Lack of access to antiretroviral treatment is a key issue that enhances or advances HIV/AIDS-related stigma and discrimination in many countries. The perceived ‘untreatability’ of AIDS is a key factor contributing to the stigmatization of many of those affected. 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 are being made to extend the availability of antiretroviral drugs. In **South Africa**, for example, the Treatment Action Campaign (TAC) was formed in 1998 with the aim of improving access to treatment and drugs for people with HIV/AIDS in South Africa. Its struggle for human rights has simultaneously deployed a number of strategies aimed at challenging stigma. Activists have made famous a T-shirt with the phrase ‘HIV-positive’ emblazoned on its front. This re-appropriation of the stigma associated with HIV/AIDS has led both wearers and observers to question what the virus does to an individual’s personality, leading to greater awareness.

In **Costa Rica**, for example, where official resistance to antiretroviral therapy was initially premised on the assumption that it was too expensive to provide, a small group of people living with AIDS—the Patient Coalition—negotiated for a year with the government. Frustrated, the group appealed to the Supreme Court in 1997 and won its support, forcing the government to begin offering antiretroviral drugs to people with HIV/AIDS. Today, a substantial number of Costa Ricans with AIDS receive combination therapy³⁸. Just as importantly, the increasing visibility of people with HIV/AIDS in this country and in other Central American republics is helping to significantly enhance awareness and challenge negative stereotypes and attitudes³⁹.

In **Venezuela**, *Acción Ciudadana Contra el Sida* (ACCSI) filed a suit on behalf of 11 people with HIV/AIDS who claimed they were not receiving proper medical attention, and their rights to non-discrimination, health, equality, access to science and technology and access to social security, as guaranteed by the National Constitution, the American Convention on Human Rights, and other conventions signed and ratified by Venezuela, were thereby being infringed. In May 1997, the court upheld the lawsuit, and ordered the Social Security System to provide treatments (including protease inhibitors) on a regular basis at no cost. Numerous other lawsuits have subsequently been successful, including those filed against the Ministry of Defence and the Ministry of Health⁴⁰.

In **Brazil**, the government, pushed by a strong activist movement, has instituted free HIV/AIDS treatment for everyone infected. Today, almost all people in Brazil have access to treatment, and mortality from AIDS has been substantially reduced. Aggressive policies combining parallel licensing and successful negotiations with pharmaceutical companies for sharp price reductions have contributed to the success. But there have been social consequences, as well. Brazil’s response to HIV/AIDS has been recognized as one of the most successful globally and, while HIV/AIDS-related social solidarity cannot be solely attributed to

³⁷ <http://www.alp.org.za>

³⁸ <http://www.aegis.com/news/panos/1998/PS980901.html>

³⁹ <http://www.aguabuena.org/ingles/articulos.html>

⁴⁰ <http://www.aidslaw.ca/Maincontent/otherdocs/Newsletter/vol5no42000/carrascodurban.htm>

the availability of treatment drugs, the widespread availability of such drugs has reportedly lessened negative responses to the epidemic⁴¹.

But even in countries with well-developed treatment-access programmes, the risk of discontinuation and interruption of treatment availability continues to be a concern. In **Argentina**, and in the wake of the serious economic problems currently confronting the country, the vulnerability of the antiretroviral-treatment-access programme has been highlighted. Here, as in other countries, there is serious concern that the distribution of medications may be in jeopardy because of the broader political and economic situation⁴².

Issues of access to treatments for HIV and AIDS are, of course, complex, and the relationship between the implementation of access programmes and combating HIV/AIDS-related stigma and discrimination requires further investigation. But it is also important to remember that, whatever their cause, inequalities in access to treatment drugs determined by, *inter alia*, price are not only unjust, they can be changed, as clearly illustrated by the joint UNAIDS/WHO Accelerating Access to HIV/AIDS Care, Support and Treatment initiative⁴³.

VIII. SOME STRATEGIES FOR SUCCESS

Too often, in the past, stigma reduction has been likened to a model of enlightenment, in which those who know best intervene to correct the bad thoughts and actions of others. This approach sees the minds of people as empty vessels waiting to be filled with the good ideas of intervention specialists and communications experts, instead of empowering communities through a participatory process that unleashes their own knowledge and experiences.

What are the key features of successful approaches? Successful approaches must be honest and relevant to the lives of individuals affected. Further, they should aim to develop accurate understanding of the epidemic, its nature and its causes. They should also seek to address the root causes of anxiety and insecurity—fear of contagion, sexuality, illness and death. And, finally, they should safeguard the dignity of individuals and respect human rights in the process and outcomes.

Given the intimate link between HIV/AIDS-related stigma, discrimination and human rights violations, *multi-pronged interventions are needed* to address each of these issues. Stigma, discrimination and human rights can be used as entry points for successful work. Thus, action must be taken to *prevent* stigma and *challenge* discrimination when it occurs, and *monitor and redress* human rights violations.

Far more successful are efforts to unleash the power of ‘resistance’ on the part of stigmatized populations and communities, so as to enable them to fully enjoy the human rights to which they, like all others, are entitled. *Ultimately, it is the power of community to challenge and to ‘take charge’ that, in many countries, has made the greatest headway against the epidemic.* This is illustrated in the work of organizations such as TASO in Uganda,

⁴¹ Ministry of Health Brazil (2000) *The Brazilian Response to AIDS*. Brasilia DF, Ministry of Health. See also <http://www.unaids.org/bestpractice/digest/files/brazilianresponse.html>

⁴² Personal communication, V. Terto Jr, ABIA, Rio de Janeiro, Brazil.

⁴³ http://www.unaids.org/acc_access/index.html

which has done much to bring HIV/AIDS out into the open, de-stigmatizing the epidemic in the process⁴⁴.

The importance of this kind of work has been well documented, especially in countries such as Brazil, where ‘popular education⁴⁵’ has been used as the basis from which to develop programmes aimed at consciousness-raising, empowerment and community mobilization. One of the key lessons to be learned from such work is the importance of tackling stigma and discrimination, not only in relation to HIV/AIDS, but also in relation to the other forms of inequality and exclusion that disempower those most vulnerable to infection.

In **São Paulo, Brazil**, for example, research has shown that, in order to implement HIV/AIDS prevention programmes for inner-city youth, it is first necessary to confront issues of poverty and economic marginalization, the stigma and racism associated with being a migrant (often from the poor north-eastern region of the country), and the unequal gender-based power relations and norms in Brazilian culture. By focusing not only on HIV/AIDS, but also on these other issues, Brazilian health promotion workers, like those in other parts of Latin America, have demonstrated the potential of what might be described as a kind of ‘community pedagogy’ as the foundation for a more effective response to HIV/AIDS⁴⁶.

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.
- The greater empowerment of people living with, and affected by, HIV/AIDS is essential for the HIV/AIDS response. The Greater Involvement of People Living with HIV/AIDS (GIPA) principle encourages the active involvement of people living with HIV/AIDS in policy-making, and in the development and implementation of programmes. Such involvement is central to de-stigmatizing the epidemic and strengthening the capacity of affected communities to fight back.
- Community mobilization, advocacy and social change must take place alongside interventions to change the broader context in which individuals and communities live⁴⁷. Local ‘ownership’ of HIV/AIDS, such as that fostered as part of building an AIDS-competent community⁴⁸, is essential to a successful response.
- Broad based 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 stigmatization at home, at school and in the community.

⁴⁴ Kaleeba N et al. (2000) *Open Secret: People facing up to HIV and AIDS in Uganda*. Oxford: ActionAid.

⁴⁵ Freire P (1970) *The Pedagogy of the Oppressed*. New York: Continuum.

⁴⁶ Paiva V (2000) Gendered Scripts and the Sexual Scene: Promoting Sexual Subjects among Brazilian Teenagers. In *Framing the Sexual Subject: The Politics of Gender, Sexuality, and Power*, ed. R.G. Parker, R.M. Barbosa, P. Aggleton, 1:216-239. Berkeley/Los Angeles/London: University of California Press.

⁴⁷ 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.

⁴⁸ <http://www.unaids.org/bestpractice/digest/files/thepromotionofcommunity.html>

- 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 to 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 and care and support services) 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.
- 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 concerns⁴⁹. 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-raising⁵⁰.
- 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.

⁴⁹ 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.

⁵⁰ 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.

Greater access to antiretrovirals can also help reduce stigmatization and discrimination as community fears lessen and HIV/AIDS is seen as a manageable disease.

- Ensure that HIV/AIDS-related subjects, including counselling skills, are included in the pre- and in-service training of religious leaders and those working in faith-based organizations.

IX. CONCLUSION

In order to respond positively and effectively to HIV/AIDS-related stigma and discrimination, work has to occur simultaneously on several fronts. Vitally important is communication and education to encourage better understanding of AIDS and HIV—the virus that causes it. Also important are steps to promote understanding and support for people living with HIV/AIDS. Their greater visibility and involvement in policy and programme development should be strongly encouraged. Only this way can harmful and divisive stereotypes and prejudices be challenged.

An equitable policy and legal context is central to success. But supportive laws, policies and practices are frequently to be struggled for. All over the world, HIV/AIDS activism has achieved an immense amount in a short time. Governments, national authorities, businesses and nongovernmental organizations have been taken to task for discriminating against, or failing to provide equitably for, people living with HIV/AIDS. But there is still much to be done.

One of the greatest challenges relates to increased access to treatment drugs. Globally, stark inequalities exist between those countries where antiretroviral treatment is available and those where it is not. Steps must urgently be taken to remedy this situation, not only because the current generation of treatments prolongs and improves quality of life, but also because the availability of treatment drugs can change perceptions of the epidemic, de-stigmatizing HIV/AIDS in the process.

In developing local responses throughout the World AIDS Campaign 2002-2003, it is essential to focus on the deeper structures of inequalities that fuel negative responses of stigmatization and discrimination. As this overview of key issues makes clear, the stigmas associated with HIV/AIDS do not arise from out of the blue. Nor, sadly, can they be made to disappear with a smile and a few kind thoughts. Without strenuous effort to tackle the social divisions of gender, sexuality, poverty and race upon which HIV/AIDS feeds, little headway can be made. This is as true in the poorer countries of the world as it is in the richer. Broad-based alliances need to be formed, therefore, between those active in preventing HIV/AIDS and promoting care and those working in other fields—for gender equality, for sustainable development, and for racial and sexual equality, for example.

Ultimately, during this year and the next, the fundamental goal should be to strive for action based on understanding—action guided by evidence and careful thought, and action grounded in the everyday experiences of people living with and affected by HIV/AIDS. Some 20 years into the epidemic, with prejudice, stigma and discrimination still evident, the time to act is now. Fine words, and stirring speeches have their place, but can be no substitute for concrete

IX. CONCLUSIONS

steps to defend the rights of people with HIV/AIDS and to promote better understanding of their needs. The World AIDS Campaign 2002-2003 provides the opportunity to do this.

As the Campaign unfolds, this initial conceptual framework and basis for action will be added to by other documents focusing on particular issues, such as the impact of antiretrovirals on HIV/AIDS-related stigma and discrimination. Case studies of country-level success will also be documented.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together eight United Nations agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its eight cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners—governmental and NGO, business, scientific and lay—to share knowledge, skills and best practice across boundaries.

The aim of this conceptual framework paper is to:

- create a common understanding of HIV/AIDS-related stigma and discrimination;
- highlight some existing interventions targeting HIV/AIDS-related stigma and discrimination; and
- contribute to effective ways of preventing stigma and challenging discrimination when it occurs, and monitoring and redressing human rights violations.

This paper will be complemented by other theme-based materials developed as part of the World AIDS Campaign such as the impact of antiretrovirals on HIV/AIDS-related stigma and discrimination.

The World AIDS Campaign for the years 2002-2003 will focus on stigma and discrimination. The main objective of the campaign is to prevent, reduce and ultimately eliminate HIV/AIDS-related stigma and discrimination, wherever it occurs and in all its forms.

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.

Self-stigmatization, or the shame that people living with HIV/AIDS experience when they internalize the negative responses and reactions of others, can lead to depression, withdrawal and feelings of worthlessness.

Discrimination against those living with HIV/AIDS, or presumed to be infected, is a violation of human rights. All individuals have a right to equal respect and dignity, whatever their health status.



Joint United Nations Programme on HIV/AIDS

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