



Joint United Nations Programme on HIV/AIDS

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# HIV-Related Stigma, Discrimination and Human Rights Violations

Case studies of successful programmes

## UNAIDS BEST PRACTICE COLLECTION



Prepared for UNAIDS  
by  
Peter Aggleton, Kate Wood and Anne Malcolm  
Thomas Coram Research Unit,  
Institute of Education, University of London, United Kingdom

Richard Parker  
Department of Sociomedical Sciences, Mailman School of Public Health,  
Columbia University, New York, United States of America

UNAIDS responsible staff: Miriam Maluwa, Senior Adviser, Law and Human Rights

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UNAIDS – 20 avenue Appia – 1211 Geneva 27 – Switzerland  
Telephone: (+41) 22 791 36 66 – Fax: (+41) 22 791 41 87  
E-mail: [unaids@unaids.org](mailto:unaids@unaids.org) – Internet: <http://www.unaids.org>

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## Background

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From the start of the AIDS epidemic, stigma and discrimination have fuelled the transmission of HIV and have greatly increased the negative impact associated with the epidemic. HIV-related stigma and discrimination continue to be manifest in every country and region of the world, creating major barriers to preventing further infection, alleviating impact and providing adequate care, support and treatment.

The stigma associated with AIDS has silenced open discussion, both of its causes and of appropriate responses. Visibility and openness about AIDS are prerequisites for the successful mobilization of government, communities and individuals to respond to the epidemic. Concealment encourages denial that there is a problem and delays urgent action. It causes people living with HIV to be seen as a 'problem', rather than as a solution to containing and managing the epidemic.

Stigmatization associated with AIDS is underpinned by many factors, including lack of understanding of the illness, misconceptions about how HIV is transmitted, lack of access to treatment, irresponsible media reporting on the epidemic, the incurability of AIDS, and prejudice and fears relating to a number of socially sensitive issues including sexuality, disease and death, and drug use.

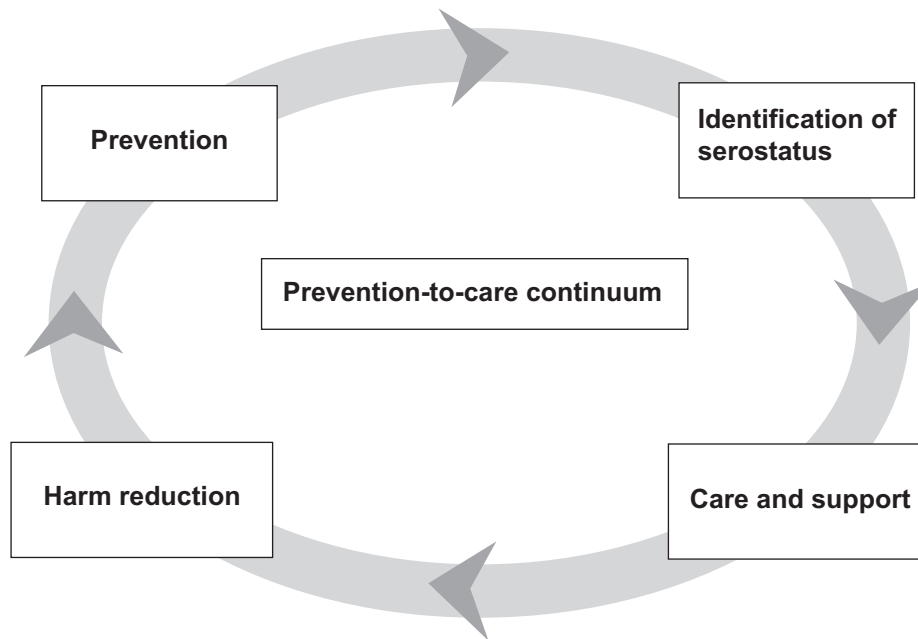
Stigma can lead to discrimination and other violations of human rights which affect the well-being of people living with HIV in fundamental ways. In countries all over the world, there are well-documented cases of people living with HIV being denied the right to health-care, work, education, and freedom of movement, among others.

Global consensus on the importance of tackling AIDS-related stigma and discrimination is highlighted by the Declaration of Commitment adopted by the United Nations General Assembly Special Session on HIV/AIDS in June 2001<sup>1</sup>. The Declaration states that confronting stigma and discrimination is a prerequisite for effective prevention and care, and reaffirms that discrimination on the grounds of one's HIV status is a violation of human rights.

Not only is HIV-related discrimination a human rights violation, but it is also necessary to address such discrimination and stigma in order to achieve public health goals and overcome the epidemic. Responses to HIV and AIDS can be placed along a continuum of prevention, care and treatment, and the negative effects of stigma and discrimination can be seen on each of these aspects of the response. Ideally, people should be able to seek and receive voluntary and confidential counselling and testing to identify their HIV status without fear of repercussions. Those who test HIV-negative should receive prevention counselling so as to be able to stay negative. Those who test HIV-positive should receive available treatment and care, and prevention counselling to protect others from infection and themselves from reinfection. People living with HIV and AIDS should be able to live openly and experience compassion and support within their communities. Their open example personalizes the risk and experience to others, thereby aiding prevention, care and treatment efforts.

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<sup>1</sup> See <http://www.un.org/ga/aids/coverage>



**Figure 1: The prevention to care to treatment continuum (Based on MacNeil and Anderson 1998, Busza 1999)<sup>2</sup>**

A stigmatizing social environment poses barriers at all stages of this cycle by virtue of being, by definition, non-supportive. HIV-related stigma and discrimination undermine prevention efforts by making people afraid to find out whether or not they are infected, to seek out information about how to reduce their risk of exposure to HIV, and to change their behaviour to more safe behaviour lest this raise suspicion about their HIV status. Thus, stigma and discrimination undermine the ability of individuals and communities to protect themselves.. The fear of stigma and discrimination also discourages people living with HIV from disclosing their HIV infection, even to family members and sexual partners. The secrecy that surround HIV infection and results from fear of stigma and discrimination causes people to imagine that they are not themselves at risk of HIV infection.

The stigma and discrimination associated with HIV and AIDS also mean that people living with HIV and AIDS are much less likely to receive care and support. Even those not actually infected but associated with the infected, such as spouses, children, and caregivers, suffer stigma and discrimination. This stigma and discrimination needlessly increase the personal suffering associated with the disease.

The shame associated with AIDS—a manifestation of stigma that has been described by some writers as ‘internalized’ stigma—may also prevent people living with HIV from seeking treatment, care and support and exercising other rights, such as working, attending school, etc. Such shame can have a powerful psychological influence over how people with HIV see themselves and adjust to their status, making them vulnerable to blame, depression and self-imposed isolation.

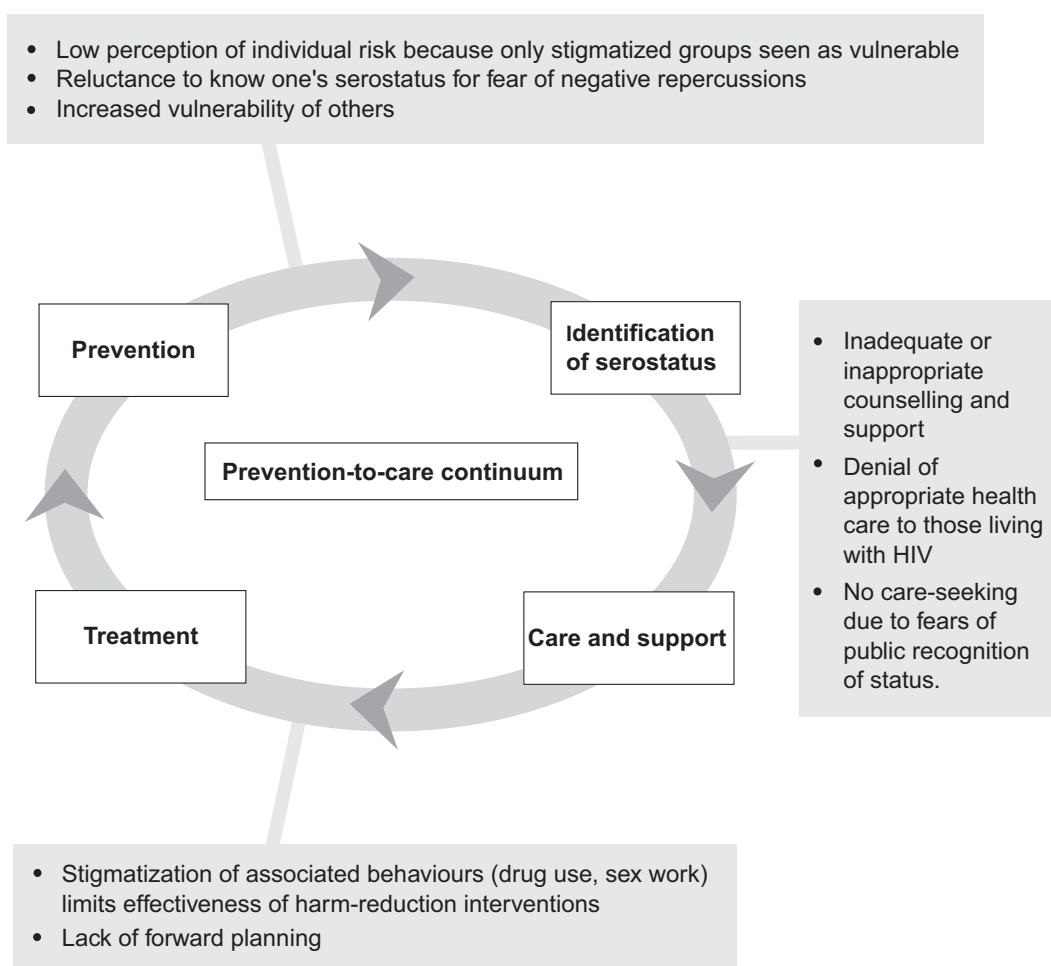
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<sup>2</sup> McNeil J. and Anderson S. (1998) *Beyond the dichotomy: linking HIV prevention with care. AIDS*, 12 (Supplement 2): S19-S26; Busza J. (1999) *Challenging HIV-related stigma and discrimination in Southeast Asia: past successes and future priorities*. Population Council: Horizons Project. [http://www.popcouncil.org/horizons/reports/book\\_report/default.html](http://www.popcouncil.org/horizons/reports/book_report/default.html)

This may be exacerbated in cases where individuals are members of particular groups that are already isolated and stigmatized, such as injecting drug users, men who have sex with men, and sex workers, or migrants. In settings where medical care is available, stigma may increase the difficulty of adhering to treatment regimens.

These patterns of non-disclosure and difficulty in seeking treatment, care and support themselves feed stigma and discrimination, reinforcing the cycle. This is because stereotypes and fear are perpetuated when communities often only recognize people living with HIV when they are in the debilitating and symptomatic final stages of AIDS, and denial and silence reinforce the stigmatization of these already-vulnerable individuals. Non-disclosure of HIV-infection within families often leads to lack of forward planning, leaving orphans and other bereaved dependents economically deprived once the bread winner dies and often marginalized, if their association with AIDS becomes known.

**Figure 2: The impacts of AIDS-related stigma and discrimination on the prevention-to-care-to-treatment continuum (adapted from Busza 1999)<sup>3</sup>**



<sup>3</sup> Diagram adapted from: Busza J. (1999) *Challenging HIV-related stigma and discrimination in Southeast Asia: past successes and future priorities*. Population Council: Horizons Project. [http://www.popcouncil.org/horizons/reports/book\\_report/default.html](http://www.popcouncil.org/horizons/reports/book_report/default.html)

## Understanding stigma and discrimination: forms and contexts

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In order to identify potential solutions to HIV-related stigma and discrimination, it is necessary to understand what is meant by these concepts, to describe how they are manifested, and to analyse the relationships between them<sup>4</sup>.

### *What is stigma?*

Stigma has been described as a dynamic process of devaluation that ‘significantly discredits’ an individual in the eyes of others<sup>5</sup>. The qualities to which stigma adheres can be quite arbitrary—for example, skin colour, manner of speaking, or sexual preference. Within particular cultures or settings, certain attributes are seized upon and defined by others as discreditable or unworthy.

HIV-related stigma is multi-layered, tending to build upon and reinforce negative connotations through the association of HIV and AIDS with already-marginalized behaviours, such as sex work, drug use, and homosexual and transgender sexual practice. It also reinforces fears of outsiders and otherwise vulnerable groups, such as prisoners and migrants. Individuals living with HIV are often believed to deserve their HIV-positive status as a result of having done something ‘wrong’. By attributing blame to particular individuals and groups that are “different”, others can absolve themselves from acknowledging their own risk, confronting the problem and caring for those affected.

Images of people living with HIV in the print and visual media may reinforce blame by using language that suggests that HIV is a ‘woman’s disease’, a ‘junkie’s disease’, an ‘African disease’, or a ‘gay plague’. Religious ideas of sin can also help to sustain and reinforce a perception that HIV infection is a punishment for deviant behaviour.

Stigma is expressed in language. Since the beginning of the epidemic, the powerful metaphors associating HIV with death, guilt and punishment, crime, horror and ‘otherness’ have compounded and legitimated stigmatization. This kind of language derives from, and contributes to, another aspect underpinning blame and distancing: people’s fear of life-threatening illness. Some fear-based stigma is attributable to people’s fear of the outcomes of HIV infection—in particular, the high fatality rates (especially where treatment is not widely accessible), fear related to transmission, or fear stemming from witnessing the visible debilitation of advanced AIDS.

Stigma is deeply rooted, operating within the values of everyday life. Although images associated with AIDS vary, they are patterned so as to ensure that AIDS-related stigma plays into, and reinforces, social inequalities<sup>6</sup>. These inequalities particularly include those linked to gender, race and ethnicity, and sexuality. Thus, for example, men and women are often not dealt

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<sup>4</sup> Parker R. and Aggleton P. (2002) HIV/AIDS-related stigma and discrimination: a conceptual framework and an agenda for action. Population Council: Horizons Project. Available at: <http://www.popcouncil.org/pdfs/horizons/sdcncptifrmwrk.pdf>. See also: Maluwa M., Aggleton P., and Parker R. (2002) HIV/AIDS stigma, discrimination and human rights – a critical overview. *Health and Human Rights*, 6, 1: 1-15.

<sup>5</sup> Goffman E. (1963) *Stigma: notes on the management of a spoiled identity*. New York: Simon and Schuster.

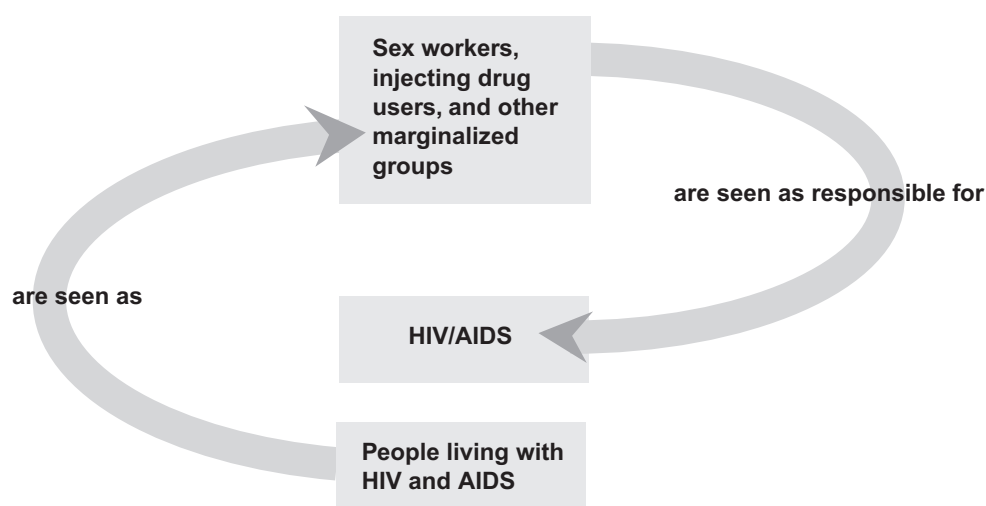
<sup>6</sup> For a theoretical elaboration of the linkages between stigma and the reproduction of social difference, see Parker R. and Aggleton P. (2003) HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine*, 57, 13-24.

with in the same way when infected or believed to be infected by HIV: a woman is more likely to be blamed even when the source of her infection is her husband, and infected women may be less likely to be accepted by their communities.

This process is linked to long-standing gender inequalities underpinned by ideas about masculinity and femininity that have historically resulted in women being blamed for the transmission of sexually transmitted infections of all kinds, and have guilt imputed to them out of assumed ‘promiscuity’. Similarly, the attribution of blame to homosexual and transgendered people builds on long-standing stigmatization related to assumptions about their lifestyles and sexual practices. Racial and ethnic stereotyping also underpins AIDS-related stigma<sup>7</sup>. The epidemic has been characterized, for example, by racist assumptions about ‘African sexuality’ and perceptions in the developing world of the West’s ‘immoral behaviour’. Finally, the vulnerability to HIV of communities living in poverty has reinforced the existing stigmatization of those people who are economically marginalized.

Through these associations, stigma is linked to power and domination throughout society as a whole, creating and reinforcing inequality whereby some groups are made to feel superior and others devalued. The association of HIV with already-stigmatized groups and practices intensifies these pre-existing inequalities, reinforcing the production and reproduction of inequitable power relations. Pre-existing stigma compounds HIV-related stigma, not simply because already-stigmatized groups are further stigmatized through association with HIV, but also because individuals living with HIV may be assumed to belong to marginalized groups.

**Figure 3: The circle of stigmatization and marginalization<sup>8</sup>**



HIV-related stigmatization, then, is a process by which people living with HIV are discredited. It may affect both those infected or suspected of being infected by HIV and those affected by AIDS by association, such as orphans or the children and families of people living with HIV.

<sup>7</sup> For an examination of the links between racism, stigma and discrimination, see <http://www.unhcr.ch/html/menu2/7/b/hivbpracism.doc>

<sup>8</sup> Adapted from Parker R. and Aggleton P. (2002) *HIV/AIDS-related stigma and discrimination: a conceptual framework and an agenda for action*. Population Council: Horizons Project.

Stigmatization can also occur on another level. People living with HIV may themselves internalize the negative responses and reactions of others—a process that can result in what some people have called self- or ‘internalized’ stigmatization. Self-stigmatization has links to what some writers have described as ‘felt’, as opposed to ‘enacted’, stigma, in that it primarily affects an individual’s or affected community’s sense of pride and worth. For people living with HIV, this may be manifested in feelings of shame, self-blame, and worthlessness, which, combined with feelings of being isolated from society, can lead to depression, self-imposed withdrawal and even suicidal feelings.

*What is discrimination?*

When stigma is acted upon, the result is discrimination. Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatized. Discrimination, as defined by UNAIDS (2000) in the *Protocol for Identification of Discrimination Against People Living with HIV*, refers to any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group—in the case of HIV and AIDS, a person’s confirmed or suspected HIV-positive status—irrespective of whether or not there is any justification for these measures.

AIDS-related discrimination may occur at various levels<sup>9</sup>. There is discrimination occurring in *family and community settings*, which has been described by some writers as ‘enacted stigma’. This is what individuals do either deliberately or by omission so as to harm others and deny to them services or entitlements. Examples of this kind of discrimination against people living with HIV include: ostracization, such as the practice of forcing women to return to their kin upon being diagnosed HIV-positive, following the first signs of illness, or after their partners have died of AIDS; shunning and avoiding everyday contact; verbal harassment; physical violence; verbal discrediting and blaming; gossip; and denial of traditional funeral rites.

Then there is discrimination occurring in *institutional settings*—in particular, in workplaces, health-care services, prisons, educational institutions and social-welfare settings. Such discrimination crystallizes enacted stigma in institutional policies and practices that discriminate against people living with HIV, or indeed in the lack of antidiscriminatory policies or procedures of redress. Examples of this kind of discrimination against people living with HIV include the following.

- Health-care services: reduced standard of care, denial of access to care and treatment, HIV testing without consent, breaches of confidentiality including identifying someone as HIV-positive to relatives and outside agencies, negative attitudes and degrading practices by health-care workers.
- Workplace: denial of employment based on HIV-positive status, compulsory HIV testing, exclusion of HIV-positive individuals from pension schemes or medical benefits.
- Schools: denial of entry to HIV-affected children, or dismissal of teachers.
- Prisons: mandatory segregation of HIV-positive individuals, exclusion from collective activities.

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<sup>9</sup> For more details, see: UNAIDS (2000) *HIV- and AIDS-related stigmatization, discrimination and denial: forms, contexts and determinants. Research studies from Uganda and India*. UNAIDS, Geneva.

See also Malcolm A. et al. (1998) HIV-related stigmatization and discrimination: its forms and contexts. *Critical Public Health*, 8(4): 347-370. See also Aggleton P., Parker R. and Maluwa M. (2002) *Stigma, discrimination and HIV/AIDS in Latin America and the Caribbean*. Available at: [http://www.iadb.org/sds/publication/publication\\_3362\\_e.htm](http://www.iadb.org/sds/publication/publication_3362_e.htm).

At a *national* level, discrimination can reflect stigma that has been officially sanctioned or legitimized through existing laws and policies, and enacted in practices and procedures. These may result in the further stigmatization of people living with HIV and, in turn, legitimate discrimination.

A significant number of countries, for example, have enacted legislation with a view to restricting the rights of HIV-affected individuals and groups. These actions include:

- the compulsory screening and testing of groups and individuals;
- the prohibition of people living with HIV from certain occupations and types of employment;
- isolation, detention and compulsory medical examination, treatment of infected persons; and
- limitations on international travel and migration including mandatory HIV testing for those seeking work permits and the deportation of HIV-positive foreigners.

Discrimination also occurs through omission, such as the absence of, or failure to implement, laws, policies and procedures that offer redress and safeguard the rights of people living with HIV.

## Stigma, discrimination and human rights: an intimate connection

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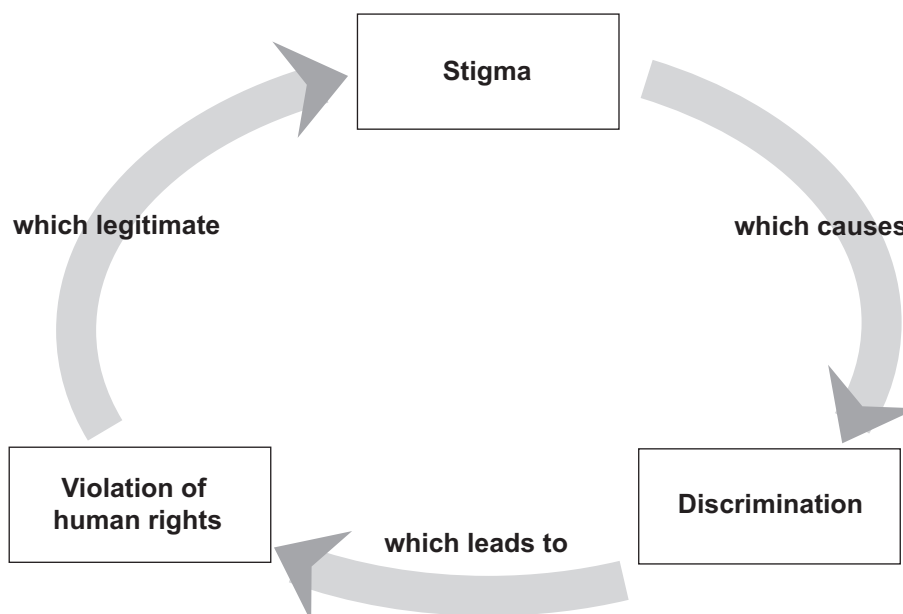
Stigma and discrimination are interrelated, reinforcing and legitimizing each other. Stigma lies at the root of discriminatory actions, leading people to engage in actions or omissions that harm or deny services or entitlements to others. Discrimination can be described as the enactment of stigma. In turn, discrimination encourages and reinforces stigma.

Discrimination is a violation of human rights. The principle of non-discrimination, based on recognition of the equality of all people, is enshrined in the *Universal Declaration of Human Rights* and other human rights instruments. These texts, *inter alia*, prohibit discrimination based on race, colour, sex, language, religion, political or other opinion, property, birth or other status. Furthermore, the United Nations Commission on Human Rights has resolved that the term ‘or other status’ used in several human rights instruments ‘should be interpreted to include health status, including HIV/AIDS’, and that discrimination on the basis of actual or presumed HIV-positive status is prohibited by existing human rights standards.

Stigmatizing and discriminatory actions, therefore, violate the fundamental human right to freedom from discrimination. In addition to being a violation of human rights in itself, discrimination directed at people living with HIV or those believed to be HIV-infected, leads to the violation of other human rights, such as the rights to health, dignity, privacy, equality before the law, and freedom from inhuman, degrading treatment or punishment.

A social environment which promotes violations of human rights may, in turn, legitimate stigma and discrimination.

**Figure 4: The cycle of stigma, discrimination and human rights violations<sup>10</sup>**



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<sup>10</sup> Diagram developed by Miriam Maluwa and Peter Aggleton.

There are many direct and indirect links between the HIV epidemic and lack of protection of human rights. Violations of rights may worsen the impact of HIV, increase vulnerability, and hinder positive responses to the epidemic<sup>11</sup>.

- *Impact.* The violation of human rights encapsulated in discrimination increases the impact of the epidemic on people living with HIV and those presumed to be infected, as well as their families and associates. For example, a person who is dismissed from his or her job because of being HIV-positive, beyond his illness, is faced with many additional problems, including lack of economic resources for his health care, as well as providing for any dependent family;
- *Vulnerability.* People are more vulnerable to infection when their civil, political, economic, social or cultural rights are not respected. For example, women's vulnerability to HIV infection is enhanced where they do not have the legal power to make choices in their lives and to refuse unwanted sex; or where children cannot realize their rights to education and information. Further, lack of access to appropriate HIV prevention and AIDS care services increases the vulnerability of other marginalized groups such as injecting drug users, refugees, migrants and prisoners
- *Response.* Where human rights are not respected, for example when freedom of speech or freedom of association is curtailed, it is difficult or impossible for civil society to mobilize themselves to respond effectively to the epidemic. In some countries, peer education is hampered by laws that refuse official registration of non-governmental organizations or groups with certain memberships (for example, sex workers).

Ensuring the protection, respecting and fulfilment of human rights is one important way of combating AIDS-related stigma and discrimination. AIDS-related stigma and discrimination and their consequential human rights violations may be addressed through the use of existing human rights mechanisms. This existing framework provides a basis for accountability and an avenue for recognizing and enforcing the rights of people living with HIV who suffer discrimination on the basis of their actual or presumed HIV-positive status to challenge such action through procedural, institutional and monitoring mechanisms for enforcing human rights, and have recourse for countering and redressing discriminatory action.

International human rights principles, provide a coherent, normative framework within which to analyse and redress AIDS-related discrimination. States are responsible and accountable, not only for the direct or indirect violation of rights, but also for ensuring that individuals can realize their rights as fully as possible. The *International Guidelines on HIV/AIDS and Human Rights*<sup>12</sup>, published in 1998 by UNAIDS and the Office of the United Nations High Commissioner for Human Rights, clarify the obligations of states contained in existing human rights instruments<sup>13</sup> and how they apply in the context of AIDS.

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<sup>11</sup> UNAIDS/IPU (1999) *Handbook for legislators on HIV/AIDS, law and human rights: action to combat HIV/AIDS in view of its devastating human, economic and social impact*. Geneva, Switzerland.

<sup>12</sup> <http://www.unaids.org/publications/documents/human/law/JC520-HumanRights-E.pdf>

<sup>13</sup> These include the Universal Declaration on Human Rights; the Convention Against Torture, Inhuman and Degrading Treatment; the International Covenant on Civil and Political Rights; the International Covenant on Economic, Social and Cultural Rights; , the International Convention on Elimination of All Forms of Discrimination Against Women; and the Convention on the Rights of the Child.

## Working for success

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Because of the intimate connection between stigma, discrimination and human rights violations, and the fact that people living with HIV are stigmatized and discriminated against in many different settings, simultaneous, multi-pronged action is needed and must be sustained over time. In order to create an environment in which stigma, discrimination and human rights violations are no longer tolerated or practised, the following actions are necessary.

- The implementation of programmes that deal with stigma at collective and community levels. Programmes need to be proactive in addressing stigma before it is manifested or enacted in various kinds of discriminatory action, rather than merely responding to it after it has occurred.
- The development and implementation of laws and policies to protect against discrimination and protect the rights of people living with HIV.

These approaches are interdependent and mutually reinforcing. Responses in one setting (e.g., in health-care services or workplaces) may have consequences for the way in which people react in others (e.g., at home). As a tool for tackling stigma and discrimination, legal and policy reforms have limited impact unless supported by the values and expectations of communities and society as a whole. Regulating the discriminatory actions that are the outcome of stigma, without addressing the understanding and attitudes that give rise to such actions, leads inevitably to an inadequate response. Stigmatization frequently occurs in contexts and settings not regulated by legislation, such as within families and everyday social encounters, and urgent action is needed in these environments to combat its occurrence.

Legal and policy reform have an important role to play in helping to change broader social values and in setting standards, both of which may lead to reduction of stigmatization and discrimination in community and institutional settings. Legal and policy reform that protect human rights in turn provides a supportive environment for the development and implementation of effective HIV prevention and AIDS care programmes. Overall, freedom from discrimination empowers individuals and communities to act, to mobilize their resources, and to respond collectively and positively to the HIV epidemic.

Ultimately, stigma, discrimination and human rights provide three key entry points for successful work:

- preventing stigma;
- challenging discrimination when it occurs; and
- promoting and protecting human rights, including monitoring and redressing human rights violations.

## Case studies

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### Introduction

Projects, programmes and activities in a range of countries have innovatively challenged HIV-related stigma, discrimination and human rights violations. While some of this work has been designed to tackle stigma and discrimination directly, other approaches have worked more holistically and indirectly, by creating supportive and enabling environments.

Evidence for the success of these in-country programmes and activities comes from a range of sources, including published documents, unpublished project reports, external evaluations and programme reviews. Some of the activities and programmes described here are in the process of being scaled up as a result of their initial success.

It is important to recognize that many programmes have not, as yet, been formally evaluated. The manifestation of positive effects of programmes that challenge stigma and discrimination and promote human rights can take time, and many factors can influence eventual outcomes. Nevertheless, across different projects, programmes and activities, there are frequently observable impacts that may be used as indicators of a successful association between programme actions and outcomes<sup>14</sup>.

In a community setting, for example, these might include:

- increased willingness of relatives and community members to care for HIV-positive people;
- enhanced care resulting in better quality of life for people living with HIV;
- increased willingness of community members to volunteer in HIV prevention and AIDS care programmes;
- increased disclosure of seropositivity by people living with HIV, and their increased involvement in, and leadership of, prevention, care and advocacy efforts;
- reduction in self-stigma and increased confidence among people living with HIV; and
- a more open expression of positive attitudes within communities towards people living with and affected by HIV and AIDS.

In health-care settings, indicators of success might include:

- increased uptake of HIV counselling and testing;
- increased access to, and uptake of, treatment;
- reduced numbers of complaints of discrimination by people living with HIV and their families;

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<sup>14</sup> For a review of primarily US-based interventions to reduce HIV-related stigma, see Brown L., Trujillo L., and Macintyre K. (2001) *Interventions to Reduce HIV/AIDS stigma: what have we learned?* Population Council: Horizons Project. For an overview of programmes challenging HIV-related stigma and discrimination in South-East Asia, see Busza J. (1999) *Challenging HIV-Related Stigma and Discrimination in Southeast Asia: Past Successes and Future Priorities*. Population Council: Horizons Project. [http://www.popcouncil.org/horizons/reports/book\\_report/default.html](http://www.popcouncil.org/horizons/reports/book_report/default.html)

- improved quality of care of HIV-positive patients, resulting in enhanced quality of life;
- increased willingness on the part of health workers to deal constructively with people living with HIV; and
- increased expression of positive attitudes towards people living with HIV by health workers in non-health-care settings.

In employment and in the workplace, indicators of success might include:

- reduction in complaints of discrimination;
- increase in volunteers within workplaces participating in specific AIDS programmes;
- increased openness of HIV-positive employees about their status;
- increased willingness of employees to work alongside people known to be living with HIV;
- increased uptake of voluntary counselling and testing;
- enhanced uptake of treatment services offered by workplaces; and
- supportive HIV workplace policies and practice.

Several of the local programmes described in the case studies are in the process of being scaled up in recognition of their benefit to people living with HIV and the communities in which they live.

Actions to help challenge HIV-related stigma and discrimination may be classified under three broad headings:

#### *Stigma-reduction initiatives*

These tend to be community-based or community-focused, and have been located within a range of prevention and care activities. They include media-directed efforts aimed at increasing tolerance towards and understanding of people living with HIV and promoting understanding of their circumstances.

Many of these initiatives have aimed to reduce stigma through the use of multiple strategies. These have included:

- improving the quality of life for people living with HIV through integrated care, including home-based care;
- mobilizing religious leaders to foster respect and compassion for people living with HIV;
- addressing broader inequalities through participatory education;
- creating a supportive and confidential space for the discussion of sensitive topics;
- providing comprehensive HIV treatment and AIDS care, including access to antiretroviral therapy;
- empowering people living with HIV to take the lead in diverse support and advocacy activities;

- mobilizing community leaders to encourage greater openness around sexuality- and HIV-related issues within communities by building on positive social norms; and
- raising awareness through the media.

*Anti-discrimination measures*

Anti-discrimination measures tend to have taken place in institutional settings—specifically workplaces or health services—and aim to de-institutionalize stigma and discrimination.

Strategies used to tackle stigma and discrimination in institutional settings include mobilizing the private sector to implement non-discriminatory policies; promoting understanding about AIDS through the education of managers and employees; improving the quality of life of employees living with HIV through access to integrated care and the implementation of non-discriminatory workplace policies; ensuring redress where cases of discrimination occur; and improving the quality of care in health services for patients living with HIV through participatory work with health-care managers and providers.

*Human rights and legal approaches*

Human rights approaches include: instituting legal action to challenge discrimination and other violations of human rights in various arenas; ensuring access to redress; conducting rights awareness campaigns, including promoting understanding among people living with HIV of their rights.

## Stigma-reduction approaches

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### **Approach: Improving the quality of life for people living with HIV through integrated care**

Project name and location

### ***AIDS Integrated Programme, Catholic Diocese of Ndola, Zambia***<sup>15,16</sup>

#### **Background**

The Ndola Diocese's AIDS Department was established in 1993. The Ndola Diocese programme provides integrated care and support for people—almost exclusively adults—who are chronically ill. Most of them have symptoms of AIDS and/or tuberculosis (TB). The programme operates 11 community-based home-care programmes in 26 low-income townships on the edges of five towns in the Copperbelt province.

By 2003, the programme was serving a population of between 350 000 and 400 000, with an estimated coverage of 73% of chronically-ill patients. The programme combines medical and nursing care, socioeconomic support, human rights and legal support, and psychological care. As elsewhere, high levels of stigma and discrimination are prevalent in the communities supported by the Ndola programme.

#### **Goals and objectives**

To provide integrated care for people living with HIV and/or TB by strengthening the capacity of families and communities to care for them; to promote awareness of ways to prevent and control HIV; and to promote community development.

#### **Key players**

The programme is funded by a consortium of donors. The Ndola Diocese AIDS Department is responsible for the programme, employing 11 full-time staff. A total of 34 nurses work in the 26 compounds in which the programme operates.

The home-care programme does not operate from a hospital or other health institution, but works as a partnership involving various departments of Ndola Catholic Diocese, working with local non-governmental organizations/community groups, district health management teams, government and private hospitals, the Victim Support Programme of the Zambian police, and a small number of local businesses.

Activities are implemented by over 750 volunteers from the community—mainly women, most of whom have formed their own committees to regulate their affairs. The volunteers are coordinated and supervised by coordinators specifically employed to do so, and by

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<sup>15</sup> Boswell D. and Banda I. (2002) *Home and community care in Zambia: and external evaluation of the AIDS integrated programme, Catholic Diocese of Ndola*. Family Health International.

<sup>16</sup> Blinkhoff P. et al. (1999) *Under the Mpundu tree: volunteers in home care for people with HIV/AIDS and TB in Zambia's Copperbelt*. Actionaid: Strategies for Hope series no. 14. <http://www.e-alliance.ch/resources/documents/pdf/SFHBook14.pdf>

‘managing agencies’ who are also responsible for the management of drugs, food and other supplies and the disbursement of funds. Managing agencies, in collaboration with volunteer groups, have considerable flexibility in the organization of activities at community level.

### **Actions taken**

- Welfare support is provided to the families of people living with HIV. Food is provided to over half of the people currently on the home-care register. TB patients, families with orphans, and patients who are destitute and abandoned receive food free of charge. Very poor families are also supplied with other basic household items.
- Support is provided to orphans in the form of school fees and nutritional support, as well as linkage and referral to other orphan support programmes.
- Free medical care is provided by a community nurse, either at a patient’s home or at a community clinic set up in the home of a volunteer or at a church. Patients tend to be referred by family members or neighbours, or self-refer. Nurses have supplies of key drugs, as well as vitamins and medical supplies, such as latex gloves. Patients requiring more specialized treatment are referred to hospital, and continuity of care is maintained. The following services are provided by the home-care programme: treatment for opportunistic infections; TB prevention, diagnosis, and the provision of Directly Observed Treatment Short Course (DOTS); sexually transmitted infection (STI) diagnosis, management and treatment; and malaria treatment.
- Nursing care is provided for people living with HIV. This is generally carried out by families, with support from volunteers and nurses. If family members are not present or are themselves chronically ill, the task falls to volunteers. Volunteers receive a two-week training course in home care adapted from a World Health Organization manual.
- Emotional support and practical help are provided to affected families by volunteers; and counselling is provided to people living with HIV by nurses and by volunteers trained in counselling.
- Support groups are jointly run with people living with HIV in each of the townships where the programme is operating. These have helped people living with HIV to live positively, and become involved in micro-credit schemes and income-generating activities. These groups vary in capacity and level of activity across sites. Four multi-functional centres offer a range of services that vary across sites but include income-generating activities (IGAs), health promotion, orphan support, skills training and limited voluntary confidential counselling and testing services to beneficiaries (people infected or affected by HIV and AIDS). Around 100 individuals are trained in forming ‘positive-living’ groups.
- Nurses provide families with information about the transmission of HIV and TB, and correct misconceptions. They also help to raise awareness about the need for people living with HIV to receive love and support from their families and friends. They help to reduce the stigmatization of people living with HIV, and people with TB, by counteracting misinformation and harmful rumours about particular individuals. They also conduct educational talks at churches and other organizations. Training is

provided to young people (in school anti-AIDS clubs), teachers, theatre groups and employees of HIV prevention programmes.

- Human rights training and legal support are offered. This includes training in human rights and gender for volunteers, religious leaders and the Victim Support Unit of the Zambian police. The home-care programme's partnership with the Victim Support Unit, established in 1997 to provide legal protection against child abuse, property-grabbing and violence against women, helps widows to protect their property from being seized by their deceased husband's families. Assistance in making wills is also provided.
- A system of incentives has been set up to encourage people to volunteer. In one area, for example, a block of land has been purchased for volunteers to farm.

### **Reported outcomes**

- The number of people who wanted to join the programme has increased rapidly. There are currently over 8160 patients on the register and over 8000 orphans have been registered. The TB control programme has achieved good results.
- Although stigma remains a challenge in this area, with evidence of discrimination against people living with HIV, including verbal abuse, accusations that individuals exploit their HIV-positive status for welfare benefits and the stigmatization of volunteers and peer educators 'by association', there are signs that progress is being made. Stigma reduction is being achieved through role modelling care, and emphasizing that people living with HIV need support and care and that close daily contact with them is not risky. By teaching family members to care for their sick relatives, neglect and abandonment are reduced.
- By promoting themselves as role models, people living with HIV have helped to encourage others to come forward for confidential voluntary counselling and testing. There are plans to position stigma reduction as a cross-cutting issue in all areas of programming, and to intensify the role played by people living with HIV in community education and stigma reduction.
- Volunteers have reported feeling less fearful of AIDS as a result of better understanding, some volunteers have felt less stigmatized and families of volunteers report greater openness within their own families about AIDS and increased knowledge as a result of a family member being a volunteer caregiver.



Project name and location

## ***Joint Ministry of Health/nongovernmental organization home-care programme for people with HIV/AIDS in Cambodia***<sup>17</sup>

### **Background**

In recognition of limited health services, the needs of increasing numbers of people affected by HIV and a growing community-focused nongovernmental organization sector in Cambodia, a pilot home-care programme began in 1998 in Phnom Penh. This took the form of a partnership between the Ministry of Health and a group of nongovernmental organizations. Work began with a pilot network of home-care teams, which employed a mix of government and nongovernmental organization workers.

The aims of this network were to pilot and test home-care services appropriate for people living with HIV and develop a model of health care in which nongovernmental organizations and government could act in partnership. An external evaluation, undertaken in June 2000 by the International HIV/AIDS Alliance, found that the programme was having a significant impact on the quality of life of people infected with and affected by HIV, that coverage was good and that costs were competitive. The programme is now being extended.

The theoretical framework for the work derives from the World Health Organization's approach to comprehensive-care planning. The four inter-related elements of this are clinical management, nursing care, counselling and social support.

### **Goals and objectives**

To provide integrated and appropriate home-care services for people living with HIV and other chronic conditions via a model of health care in which nongovernmental organizations and government act in partnership.

### **Key players**

The Cambodian Ministry of Health, a coalition of nongovernmental organizations including Khmer HIV/AIDS NGO Alliance, World Vision and local nongovernmental organizations, local health services, community volunteers, and people living with HIV and AIDS and their families.

### **Actions taken**

- Home visits, counselling and demonstration of local forms of care and treatment are provided, resulting in the normalization of close contact with people living with HIV. There are currently 20 urban home-care teams in Phnom Penh and others in rural areas. All the teams are composed of two part-time government nurses, and between one and three full-time nongovernmental organization AIDS staff, as well as several community volunteers. The urban teams are located at municipal health centres throughout the city. For patient visits, each home-care team splits into two groups, and patients are visited by one or other of the groups between one and three times per week. The teams carry simple medicines and supplies in specially designed home-care kits, and provide counselling, education and welfare support. Volunteers recruited from the community are becoming an increasingly important element in the

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<sup>17</sup> Wilkinson D. (2000) *An evaluation of the MoH/NGO Home care programme for people with HIV/AIDS in Cambodia*. Brighton, International HIV/AIDS Alliance.

project. Each home-care team is assisted by five to ten volunteers, each of whom is expected to work approximately 10 days per month, for a modest stipend. Some of these volunteers are themselves people living with HIV.

- Palliative care is provided to chronically ill patients, of whom people living with HIV comprise approximately 80%. Offering services to other chronically ill patients means that this project is not seen as exclusive or ‘identifying’ of people living with HIV.
- The focus is multisectoral. Links and referrals are made to other local health services, both in the state and traditional sectors. Project staff members liaise with religious leaders in the local temples to ensure the access of people living with HIV to traditional funeral services. Volunteers play a particularly important role in accessing local authorities, leaders and traditional healers.

## Reported outcomes

- The project has led to reduced suffering, increased confidence and better quality of life for people living with HIV. The evaluation<sup>18</sup> reported that 92% of patients felt that, without the home-care teams, their lives would be significantly more difficult in terms of isolation, feelings of hopelessness and loss of confidence, lack of support and having no one to care for them. The evaluation found also that 63% of patients felt that the home-care team had helped to change their outlook on the future to a more positive one.
- Following home-care team involvement 79% of family members felt that they could cope better with having a person living with HIV in their family. The husband of one HIV-positive woman, for example, said: “I used to be angry with her because I spent all my time and money looking after her. The home-care team gave me encouragement and support. I now understand better and I can care for her. Without them, it would have been impossible”.
- The project is increasing understanding of AIDS by strengthening home-based care, and through provision of such care helping to reduce stigma and discrimination against people living with HIV in the community. Although some families reported that they had not experienced discrimination prior to the start of the home-care programme, 42% of family members and 33% of patients reported reduced discrimination by their communities as a result of home-care visits. In addition, 31% of people living with HIV felt that home-care visits had improved the way in which they were treated by their families. Community leaders reported that, as a result of the home-care project, they had witnessed a reduction in discrimination, anger and fear, and increased support, understanding and sympathy towards people living with HIV in the community. Increasingly high levels of community-based referrals to the project also provide an indication of its success. In particular, increased referrals from neighbours and other patients suggest reduced discrimination against people living with HIV and increased trust in the home-care teams.
- The project has played an important role in encouraging disclosure. Although half of the people living with HIV who were interviewed by the evaluation team said that they kept their HIV status secret from their community, 45% said that the home-care teams had increased their comfort in sharing information about their HIV status with others. An increasing number are willing to ‘go public’, beyond disclosing in support groups.

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<sup>18</sup> Wilkinson D. (2001) An evaluation of the MoH/NGO home care programme for people with AIDS in Cambodia. Available at: <http://www.aidsmap.com/en/docs/0FD10339-87FF-11D5-8D06-00508B9ACEB1.asp>.

## **Approach: Mobilizing religious leaders to foster respect and compassion for people living with HIV and AIDS, and participate in prevention activities**

Project name and location

### ***Sangha Metta project, Thailand***<sup>19</sup>

#### **Background**

The Sangha Metta (‘Compassionate Brethren’) project was initiated by a lay Buddhist teacher on the Lanna campus of Mahamakut Buddhist University in Chiang Mai, northern Thailand in 1997. The aim was to respond to community needs relating to HIV prevention and care. The rationale was to use existing community resources to respond to the AIDS epidemic and extend the traditional role that Buddhist monks and nuns play in social welfare in the region.

#### **Goals and objectives**

To mobilize Buddhist monks, nuns and novices to play a role in community responses to AIDS through their participation in prevention and care activities based on understanding, compassion and community solidarity.

#### **Key players**

Buddhist monks and nuns, people living with HIV, local communities.

#### **Actions taken**

- The project trains monks, nuns and novices in AIDS-related concerns, equipping them with participatory management skills and tools to work in their communities in order to prevent HIV infection and provide support for affected families. A crucial part of the training involves promoting positive attitudes among monks and nuns through close contact with people living with HIV—for example, by eating food prepared by them. Buddhist doctrine and, in particular, the teachings on suffering and compassion contained in the Four Noble Truths and the Four Sublime States, is used to emphasize the importance of compassion and awareness in responding to people living with HIV.
- Seminars are run with local monastic and lay community leaders to raise awareness of the impact of AIDS on their communities, motivate communities to accept HIV prevention and care as part of community development activities, and help them devise strategies to conduct HIV prevention and AIDS care activities.
- Using Buddhist ethics such as the Five Precepts and the Noble Eight-fold path as their guideline, project-trained monks teach villagers how to reduce high-risk behaviour, how to gain awareness of HIV, and how to prevent prejudice and discrimination.
- Monks conduct home visits and demonstrate care towards people living with HIV, providing Buddhist-based counselling and advice on home-based care.

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<sup>19</sup> <http://www.buddhanet.net/sangha-metta/project.htm>

- Monks ensure that people living with HIV can maintain a spiritual life, providing training in meditation and organizing daily or weekly meditation retreats.
- Assistance is given to families to help with the costs of burial, ensuring that people who have died as a result of AIDS receive traditional funeral rites. A funeral robes bank is maintained for the use of affected families.
- Support, including a milk bank, and assistance with accommodation, food and schooling, is offered to HIV-affected orphans.
- Local support groups are jointly run with people living with HIV.
- Monks and nuns operate a medicine bank and collection of alms (including basic household items such as food and toiletries) for distribution to people living with HIV.
- In a country where many people are infected with HIV through injecting drug use, monks use traditional Buddhist techniques of debate to encourage street children and other young people to discuss and recognize the dangers of substance abuse.
- Monks conduct awareness-raising events within their communities, advertising 'HIV-friendly temples' to promote the integration of people living with HIV into communities, and broadcasting presentations by people living with HIV and temple discussions to local communities.

### Reported outcomes

- Training and support are being provided to a growing body of Thai monks and nuns (currently numbering over 3000). By putting compassion into practice and raising awareness, monks have helped to promote openness and acceptance towards people living with HIV and to dispel myths relating to the transmission of HIV through casual contact. The respect given to monks has meant that a gesture as simple as a monk accepting and eating alms from someone with HIV has helped to reduce the fear and stigma associated with the disease. For people living with HIV and their families, what seems to be more important than the material support offered is the unconditional acceptance by those who are highly respected in their communities.
- Since local people are accustomed to telling monks their difficulties, monks become a conduit for supporting many HIV-positive people who have not disclosed their status to others. Once disclosed to the monks, if they wish such people they can be referred to support groups and assistance programmes.
- People living with HIV are now taking a more active part in community and temple festivals. After such public events, some individuals contact the organization and are willing to disclose their status or admit that some members of their families are living with HIV.
- The Sangha Metta project has assisted in establishing similar programmes in six neighbouring countries: Bhutan, Burma, Cambodia, China, Laos and Viet Nam.

The Sangha Metta training model has also been used successfully with Christian, Hindu and Islamic leaders from Sri Lanka, Nepal, Pakistan and Afghanistan. Similar activities are now being conducted in those countries and an inter-faith network is being established.

- The following are specific examples of ways in which stigma has been challenged in communities:
  - ❖ Monks in Viet Nam spoke with community members who were trying to close an office providing support for people living with HIV. The community changed its decision and is now assisting with the work.
  - ❖ HIV-positive women have been accepted into women's groups in villages in northern Thailand after intervention by monks.
  - ❖ HIV-positive children previously denied admission to school have now been admitted.
  - ❖ Grandparents who removed their grandchild from her HIV-positive mother's care have now returned the child, following advice and education from monks.
  - ❖ A young woman in north-eastern Thailand who was rejected by her family is now back at home receiving family support and care following intervention by monks.
  - ❖ Community members are increasingly assisting at funerals of people who have died of AIDS-related illnesses.
  - ❖ Buddhist universities in north-eastern and northern Thailand have recruited people living with HIV to be resource persons during seminars and trainings.
  - ❖ A Buddhist university in north-eastern Thailand recently awarded an honorary social science degree to a woman living with HIV in recognition of the work she has done in AIDS education and awareness-raising.



Project name and location

## *Catholic AIDS Action, Namibia*<sup>20</sup>

### **Background**

Established in 1998, following the granting of approval by the Namibian Catholic Bishops' Conference, Catholic AIDS Action was the first national, faith-based response to the HIV epidemic in Namibia. With 13 offices across Namibia, it aims to inspire and support programmes of HIV prevention, home-based care, voluntary counselling and testing, spirituality, and orphan support.

### **Goals and objectives**

To challenge the HIV epidemic by having the 'courage to fight and the strength to care', by building on the work of Roman Catholic-affiliated groups and institutions to inspire and support prevention and care programmes.

### **Key players**

People living with or affected by HIV, church leaders, local communities, and volunteers.

### **Actions taken**

- Catholic AIDS Action is involved in HIV prevention activities. Trained volunteers give talks about AIDS at church meetings, schools and community events. They use these opportunities to encourage communities to be more open about the reality of AIDS, to combat stigma and dispel misinformation about HIV transmission. Although they do not distribute condoms, volunteers provide factual information about condoms and about where they can be obtained. After much internal debate, Catholic AIDS Action decided to adopt an approach to HIV prevention that would promote Christian values, while also emphasizing the importance of safeguarding human life through safer sexual behaviour. Their advice is as follows:

**A** is for abstinence from sex before marriage;

**B** stands for Be faithful in marriage. But if you find that you cannot follow this teaching, then choose;

**C** for Condoms.

- The home-based-care programme is supported by over 1500 trained volunteers, assisting over 4000 clients and over 18 500 orphans. Operating in small groups, volunteers conduct home visits to people with a chronic illness (most of whom are HIV-positive), helping with practical tasks, making referrals to local health centres and hospitals, dispensing basic medicines and vitamins, and providing spiritual support. Volunteers are given small incentives.
- Catholic AIDS Action operates three multipurpose centres where people living with or affected by HIV can go for information, counselling and legal advice, income-generating activities, support groups, orphan support services and food parcels. Two

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<sup>20</sup> <http://www.caa.org.na>. For more details, see Byamugisha G. et al. (2002) *Journeys of faith: church-based responses to HIV and AIDS in three southern African countries*. TALC.

of these centres offer voluntary counselling and testing. A volunteer doctor is on hand once a week for consultations, referrals and to dispense a limited amount of free, non-prescription medication. The centre has a small library of AIDS-related literature and videos that are used in training and outreach activities. Free advice on legal matters is provided once a week by the Legal Assistance Centre. Based on the success of this centre, other regional centres have been opened. Two of them offer voluntary counselling and testing, and there are 10 soup kitchens in operation.

- In an effort to break the silence surrounding AIDS, Catholic AIDS Action has undertaken a series of high-profile events, including conferences on ‘Living positively with AIDS’, a march and public rally, and an official disclosure event of a group of HIV-positive people from the organization *Lironga Eparu*.
- Training has included work with church leaders around stigma and discrimination. In 2002, six workshops were conducted for bishops, priests, religious sisters and deacons over three days each. One module dealt with stigma and discrimination, using role play and group work. A discussion was also held on how the official church contributes to stigma and what can be done to reduce it. Archbishop Bonifatius, the Head of the Roman Catholic Church in Namibia, attended the first workshop. He praised the openness of Catholic AIDS Action on difficult issues, including the role of condoms in HIV prevention.
- Training courses are run with youth leaders, health-care professionals and other community members in community mobilization, home-based care and HIV counselling. Work with young people includes peer-education training programmes for behavioural change—in particular, ‘Stepping Stones’ and ‘Adventure Unlimited’. More than 8000 young people have been reached through these programmes.

### Reported outcomes

- Church leaders who participated in the training workshops felt that the experience was powerful and gave them new insights. The bishops and most of the parish leaders continue to be very supportive, with most of them interested in starting youth HIV-prevention activities in their parishes.
- During the opening of the new multipurpose centre in Keetmanshoop in May 2003, a festive Eucharistic celebration took place with hundreds of volunteers and people living with HIV. During the opening ceremony, a person living with HIV disclosed his/her status.
- The Administrator of the Diocese in the South makes weekly home visits to people living with HIV.
- The last official action of the previous Archbishop Bonifatius Haushiku before he died in June 2002 was signing the foreword of the booklet, *Following in the Footsteps of Jesus*, which was an outcome of the training workshops. This work was important to him and remains his legacy to the organization.
- The pastoral centre in Doeбра has a large area dedicated to crosses with red ribbons. People bring their own crosses over the year, especially on Good Friday, with a message by which to remember the dead or with intercessions for the sick. This initiative was started by a religious brother and his superior after attending the training workshops.

## **Approach: Providing comprehensive community-based AIDS treatment, including access to antiretroviral therapy**

Project name and location

*HIV Equity Initiative, Haiti*<sup>21,22</sup>

### **Background**

Since 1987, a non-profit organization called Partners in Health (affiliated with Harvard Medical School) and its sister organization, *Zanmi Lasante* (Haitian Creole for 'Partners In Health'), have been providing health care in Cange in the Central Plateau region of Haiti. Together, they run a number of programmes, including a full-service hospital, a TB treatment facility, a women's health centre, schools, water protection efforts, and income-generating projects. HIV-prevention activities began in 1988, and included the development of culturally appropriate handbooks, videos and curricula. The group also pioneered free voluntary counselling and testing in central Haiti and was the first to introduce zidovudine (AZT) for the prevention of HIV transmission from mother to child.

In 1998, the programme enrolled its first patients in the HIV Equity Initiative, a community-based HIV-treatment programme, which provides people living with HIV with antiretroviral therapy. Using a community-based health network linked to a medical centre called *Clinique Bon Sauveur* (established in 1985), the team has implemented one of the first integrated HIV-prevention-and-care programmes in a low income country.

### **Goals and objectives**

To bring the benefits of medical science to those most in need of them and to serve as an antidote to despair, by providing high-quality health care in resource-poor settings, and establishing solidarity-based relationships with sister organizations in those settings.

### **Key players**

People living with HIV, local communities, community health workers, and health-care professionals

### **Actions taken**

- Community health-worker teams provide services for a population of one million, including screening for TB and malnutrition, vaccinations, health education, family planning, basic medical diagnoses, and referrals to the medical facility. At the health facilities, STI and TB screening and treatment are provided. At present, *Zanmi Lasante* and PIH provide high-quality medical care daily to 200–300 patients, most of whom cannot afford treatment in other clinics, including public health facilities.
- From the mid-1990s, antiretroviral therapy was introduced to pregnant women for the prevention of vertical transmission of HIV.

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<sup>21</sup> <http://www.pih.org>

<sup>22</sup> Farmer P. et al. (2001) Community-based approaches to HIV treatment in resource-poor settings. *Lancet*, 358: 404–409.

- In late 1998, a pilot HIV-treatment programme was begun with the provision of antiretroviral therapy to 50 patients with advanced AIDS, who were no longer responding to syndromic management of opportunistic infections. In the absence of viral load and CD4 testing, clinical criteria are used to enrol patients in the treatment programme. Antiretroviral therapy is provided only to symptomatic patients, and not all of those with symptoms are enrolled. (Many have active TB and other opportunistic infections and respond well to treatment of those infections.)

Following the success of the pilot programme, the initiative was expanded. A system of directly observed antiretroviral therapy is currently being provided to about 1150 people living with HIV in Haiti's central plateau. This represents 15.3% of the estimated HIV-positive patient population, which is approximately 7500 people.

The project is modelled on their community-based TB-treatment programme that was launched in 1988 and has had great success in treating TB. A similar approach has led to high rates of cure even for multi-drug resistant (MDR) strains of TB. The success of the HIV Equity Initiative is largely due to the active participation of community health workers, some of whom are HIV-positive. As in Directly Observed Treatment, Short Course (DOTS) for TB, each patient is assigned an *accompagnateur* (companion) who observes the ingestion of the medications daily and offers support to the patient and her/his family. Several patients who are the beneficiaries of DOT-antiretroviral therapy have themselves become *accompagnateurs*.

Over the coming years, Zanmi Lasante will scale up community-based HIV prevention and care throughout the lower Central Plateau. As of June 2003, four new satellite clinics, all of them public institutions, have worked with Zanmi Lasante to train scores of *accompagnateurs*, begin voluntary counselling and testing and enroll new patients. At each site, the team aims to improve not only HIV prevention and AIDS care, but also TB case-finding and treatment, antenatal and women's health and treatment of sexually transmitted infections.

### Reported outcomes

- Serious side-effects have been rare and readily managed. Adherence to the drug regimen has been excellent and the clinical response in patients dramatic. Mortality has been nil among the first 100 patients to receive at least a month of outpatient DOT-antiretroviral therapy, which has had a dramatic effect on demand for such care.
- The demand for care is reflected in a strikingly increased uptake of confidential voluntary counselling and testing services. In the knowledge that effective treatment is available, more people are coming forward for HIV testing. Since 1998, demand for voluntary counselling and testing services in rural Haiti has increased more than fivefold. This suggests that access to antiretroviral therapy is increasing openness around AIDS by helping people to understand that it is a chronic illness that may be managed. This substantial rise in the numbers seeking testing was first seen after the introduction of AZT (and combination antiretroviral therapy) to antenatal attenders, with more than 90% of women accepting the offer of HIV testing once antiretroviral drugs were made available free of charge. At the same time, the increase in demand for testing is providing increased opportunities for counselling and advice about HIV prevention. HIV-associated hospitalizations have decreased, as has TB incidence.

- There is evidence that access to antiretroviral therapy has lessened the impact of stigma for people living with HIV and their families, by transforming an otherwise fatal and physically debilitating illness into a chronic and manageable one. This enables people to once again become active members of their communities. One example is the case of a Haitian man who, before taking antiretroviral therapy, showed visible signs of wasting and experienced stigma and discrimination within the community and within his family. Once enrolled in the treatment programme, he gained nearly 14 kg in two months. “I was a walking skeleton before I began therapy,” he says. “I was afraid to go out of my house and no one would buy things from my shop. But now I am fine again... My wife has returned to me and now my children are not ashamed to be seen with me.”
- Although careful ethnographic research has yet to be conducted, it is clear that the advent of antiretroviral drugs has led to improved morale among patients and health-care providers alike. There has been excellent staff retention and many of *Zanmi Lasante*'s nurses and doctors regard HIV prevention and AIDS care as gratifying work.



## **Approach: Empowering people living with HIV to take the lead in diverse support and advocacy activities**

Project name and location

### ***Involvement of People Living with HIV in HIV-Prevention Activities, Belarus.***

#### **Background**

The nongovernmental organization 'Positive Movement' was founded in Belarus in 1999. Based in Minsk, the organization aims to provide support for people living with HIV and AIDS and their relatives. People living with HIV, their families, as well as doctors, psychologists and sociologists are members of the organization. Positive Movement currently implements two UNDP projects: 'Provision of Quality Comprehensive HIV-prevention Services to Drug Users in Belarus' and 'Involvement of People Living with HIV in HIV/AIDS-prevention Activities'. The first phase of this second project, which was funded by UNAIDS and began in September 2001, focused on providing psychological support to people living with HIV. Subsequent activities have broadened the focus to include promoting the involvement of people living with HIV in prevention activities. The focus project, in line with the theme of the 2002-2003 World AIDS Campaign, is on changing stigmatizing attitudes towards people living with HIV.

#### **Goals and objectives**

To prevent the further spread of HIV in Belarus through involving people living with HIV and their relatives in community-based prevention activities; and to minimize the negative effects of the epidemic on society as a whole, and on particular groups and individuals, through the provision of psychosocial support and anti-stigma activities.

#### **Key players**

People living with HIV, their relatives, other affected individuals (including doctors), and local communities

#### **Actions taken**

- A weekly self-help group for people living with HIV has been established.
- Group and individual therapy is provided by professional psychologists.
- A telephone hotline is run on issues relating to HIV. This is operated by trained consultants who include people living with HIV, and provides information and emotional support. Consultants invite callers who need professional psychological support to visit project psychologists. Initially, the hotline operated only twice a week. It is now open five days a week. About 30 to 40 people call the hotline monthly.
- Legal advice is provided for people living with HIV.
- People living with HIV are involved in diverse activities aimed at preventing HIV. Several people are involved in recruiting new members to AIDS support groups, visiting the National Centre for AIDS Prevention and clinics, and offering information and emotional support to those testing for HIV. Some volunteers provide counselling on HIV using the Internet. Two volunteers are in correspondence with HIV-positive prisoners. Other volunteers meet with schoolchildren and university students to discuss drug use and HIV from their own experience. Volunteers also distribute leaflets among young people in Minsk.

- A rights-based public information and advocacy campaign is being run to raise awareness about, and reduce, HIV-related stigma and discrimination. This includes a photo exhibition/installation called 'The Door', which describes the ways in which HIV enters into people's lives and how it changes them. This campaign includes ongoing interactions with the mass media and government departments.

### Reported outcomes

- With the support of staff from the National AIDS Centre. People living with HIV are given access to information, group and individual psychological support, legal advice and medical care. Members of the support groups have established informal supportive relationships with each other outside the official meetings. Discussion in the support groups is wide-ranging, with the emphasis shifting from speaking about HIV, illness and dying to discussing broader life issues. Some members of the groups have felt empowered to articulate their needs and interests in broader ways, such as by writing letters to government and the general public. Ten people living with HIV participated in a seminar in May 2003, entitled 'Needs of people living with HIV/AIDS', and entered into a dialogue with medical practitioners. This was the first time that members of the project had spoken openly about their HIV status and the issues affecting them.
- Project experiences in providing social and psychological support have been disseminated nationwide by means of a seminar for people living with HIV and professionals involved in their care. During the seminar, project volunteers and specialists from the National Centre for AIDS Prevention engaged in dialogue not only about clinical aspects of HIV, but also about the social consequences of the epidemic and the perspectives of those living with HIV.
- Increasing numbers of people living with HIV who are involved in the project are willing to disclose their HIV status. At the beginning of the project, the overwhelming majority of people living with HIV felt unable to take part in actions that involved disclosure, and few requested legal advice. During 2002, however, eight appearances of people living with HIV were organized on different TV channels. Two young men were interviewed openly, and five articles containing the life-stories of people living with HIV were published in newspapers and magazines. The difficulties associated with stigma and discrimination against people living with HIV was discussed in these articles. Despite evidence of increasing openness among people living with HIV themselves, however, close relatives and friends of those living with HIV remain reluctant to participate in project activities. Involving families remains more challenging than making contact with people living with HIV.
- In May 2003, all HIV-positive volunteers and other members of Positive Movement were involved in the organization of a regional conference called 'Increasing possibilities for advocacy of people living with HIV and AIDS in Newly Independent States', which was held in Minsk as part of the project with the financial support of UNAIDS, the Ford Foundation and the Tides Foundation. Participants from 21 countries were involved in discussion and training relating to actions that might be taken to eliminate discrimination from the lives of people living with HIV. A small grants fund was formed by donors, and participants are able to apply for financial support for advocacy activities in their own countries.

## **Approach: Counselling and support to HIV-affected families, including children, through 'succession planning'**

Project name and location

### ***Succession planning, Uganda***<sup>23</sup>

#### **Background**

Care and support services for people living with HIV have rarely been linked to ongoing support for their children. Succession planning offers an innovative approach for supporting AIDS-affected children and their families while the parents are still alive and in a position to make a difference in their children's lives. It has been developed in recognition of several key facts. First of all, children are made vulnerable long before parental death from AIDS. Despite their children's wishes for open communication, most parents hesitate to discuss the situation with their children. Finally, HIV-positive parents, their children and future ('standby') guardians are concerned about the future, yet rarely make tangible arrangements for guardianship, schooling and other issues. Succession planning helps them prepare for and discuss the future.

#### **Goals and objectives**

To engage HIV-positive parents in planning for the future of their children in order to ensure their long-term well-being, by supporting parents in appointing guardians for their children; preparing wills; disclosing their serostatus; starting income-generating projects; and creating memory books; supporting standby guardians in preparing for their future responsibilities; and alleviating worries and improving the current and long-term well-being of children whose parents are HIV-positive.

#### **Key players**

Families affected by HIV and their communities, Plan/Uganda, Population Council/Horizons Project, Department of Sociology at Makerere University.

#### **Actions taken**

Succession planning is being conducted with HIV-positive parents, their children (aged five to 18 years-old) and future ('standby') guardians. Activities include:

- Counselling for HIV-positive parents on serostatus disclosure to children through memory books and other means. Memory books were pioneered in Uganda by a programme for HIV-positive women sponsored by the National Community of Women Living with AIDS. They contain photographs, family trees, anecdotes and other family information, and can be used to break the news to children that their parent is HIV-positive.
- Support to parents in relation to designating 'standby' guardians. Parents are encouraged to appoint as guardians trusted relatives or friends, familiar to and liked by the children, with the means to provide for additional dependents. Ideally, guardians are in the same community as the AIDS-affected family, so that the children will not be uprooted or be in an unfamiliar household once the parents dies.

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<sup>23</sup> Research summary available at: <http://www.popcouncil.org/pdfs/horizons/orphanssum.pdf>. Gilborn L. et al. (2002) *Impact of a succession planning program in Uganda*. Presentation at the XIV International AIDS Conference, Barcelona. Gilborn L. et al. (2002) *Making a difference for children affected by AIDS: baseline findings from operations research in Uganda*. Population Council: Horizons Project.

- Free training to enhance legal literacy and intensive support from counsellors to encourage will-writing. It is hoped that training HIV-positive parents in will-writing will reduce property-grabbing, which affects many survivors, especially women and children.
- Assistance with school fees and supplies for children.
- Income-generation training and seed money to encourage small business enterprises.
- Community sensitization to the needs of orphans and vulnerable children.

## Reported outcomes

The Horizons Project and the Department of Sociology at Makerere University conducted operations research on the succession planning programme implemented by Plan/Uganda to explore its acceptability and impact, and to determine if succession planning (added to the provision of care services for people living with HIV) helped HIV-positive parents to plan for their children's future. The study included intervention and comparison groups, with surveys conducted before and two years after the succession planning started in the intervention group. Preliminary results indicate the following:

- Succession planning was associated with an increase among parents in appointing guardians for their children, and in disclosing their HIV status to older children. At baseline, 56% of parents had arranged a guardian for their children. Two years after the initiation of the succession planning project, this figure had grown to 81%. At baseline, despite the fact that most parents and older children (aged over 13 years) favoured parent-to-child disclosure, only 51% of parents (who were subsequently enrolled in succession planning) had disclosed their status. Two years on, 75% of respondents in the succession-planning group had disclosed.
- Succession planning doubled the number of parents who wrote wills, although the numbers still remain small. Although, at baseline, 21% of older orphans and 28% of widows had experienced 'property-grabbing', only 10% of HIV-positive parents had written wills. This proportion doubled after two years among those parents living in the area where the succession-planning project was operating. However, barriers remain, including the fact that writing wills is not a traditional practice, ongoing patterns of inheritance disfavoured women and children, low levels of literacy, and widespread fears that 'planning for death' will bring bad luck or misfortune. Concerted efforts will need to be made by community leaders and policy-makers to uphold women's property rights. Many obstacles to will-writing remain within communities.
- There is evidence that some of these practices have spread to other areas not participating in succession planning, possibly through a diffusion of ideas. The research team was puzzled to find that improvements in some outcome variables directly related to the succession-planning programme were also found among the comparison group (although often to a lesser degree of magnitude). This unexpected finding was discussed with counselling aides, who explained that news of the succession planning programme had spread to comparison areas, where communities were demanding the same services. Because some of the same organizations and counselling aides work in both study areas, it is possible that they responded to this demand in an *ad hoc* fashion. This spillover effect limits the study's capacity to draw

statistical inferences concerning the programme's impact. However, it may also be a testimony to the succession-planning programme's appeal and acceptability.

- Suggestions were made to extend succession planning services, including those dealing explicitly with death, such as will writing and memory books, to the entire community. There was a realization that everyone is mortal, whether living with HIV or not, and that it would be beneficial to take steps to ensure that loved ones would be provided for. This personalized the issues facing people living with HIV, and positioned them as role models.
- Counselling aides who are implementing the succession planning programme report that the programme was associated with increasing acceptance of people living with HIV in the community. Counsellors observed that as HIV-positive parents became more proactive about their own health and the welfare of their family, more hopeful and, in some cases (perhaps due to increased hopefulness and access to income and food) more healthy. They stated that, prior to this programme, people living with HIV were seen as helpless, non-productive, passive members of the community. Seeing people living with HIV constructively engaged in making a difference for themselves and their families turned this image on its head.
- The presence of succession planning has led to a marked increase in the demand for voluntary counselling and testing in the community. It appeared that the services were attractive enough to inspire many people in the community to test for HIV to see whether they qualified. Although beyond the scope of the research that was carried out, the net effect of this may be that a greater proportion of people living with HIV in the community are coming to know their status and to access care services, including succession planning, and a greater proportion of HIV-negative community members are realizing that they still have the opportunity to avoid exposure to HIV. This experience offers an example of high-quality community-based care enhancing not only care but prevention, and the mutually-reinforcing nature of high-quality prevention and care services.



## **Approach: Addressing broader inequalities through participatory education**

Project name and location

*Centre for the Study of AIDS (CSA) at the University of Pretoria, South Africa*<sup>24</sup>

### **Background**

The Centre for the Study of AIDS (CSA) was established in 1999 to ensure that the University of Pretoria as a whole was able to plan for, and cope with, the impact that AIDS is having on the institution and tertiary education sector as a whole. It has been active in fostering a climate of openness and debate so that policy- and decision-makers are cognisant of the issues and able to address AIDS in a range of settings, through programmes and services, and by challenging racist and prejudiced attitudes among staff and students.

### **Goals and objectives**

To make AIDS-related activities mainstream throughout the University of Pretoria, to ensure that the university as a whole is able to plan for, and cope with, the impact of HIV and AIDS. Through its activities, the CSA aims to establish the University as a place in which the key provisions of the National AIDS Policy can be implemented, including voluntary counselling and testing, education, support, research, policy and the enforcement of human rights. It also aims to create an environment wherein staff and students feel secure and supported, should they wish to disclose their HIV-positive status.

### **Key players**

Senior management, university deans and faculties, staff, students, unions, local communities, and people living with HIV.

### **Actions taken**

- An Inter-Faculty Committee, involving representatives from all faculties within the university, has been established to ensure that AIDS is on the agenda and is being addressed in all areas of curriculum innovation, development and research.
- An intensive ‘AIDS in the Workplace’ programme has been introduced for administrative as well as academic staff to ensure that staff are well versed in AIDS legislation, good practice in the workplace, establishment of support structures, managed health care, and education and training.
- Through the implementation of the GIPA principle (greater involvement of people living with or affected by HIV), people openly living with HIV are employed in the CSA to run support groups for staff and students. They are also actively involved in training and policy development.
- Collaboration with the university’s Centre for Human Rights emphasizes the rights and responsibilities of staff and students, as well as ensuring that the university remains committed to challenging racism, stigma and prejudice wherever they occur.

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<sup>24</sup> <http://www.csa.za.org/>

- The education programme for students situates AIDS within broad and critical debates on race and racism, culture, class and gender. This, together with work to promote citizenship, accountability and governance through leadership training allows for new understandings and explanations of AIDS to emerge, and creates a new understanding of, and commitment to, behavioural change.
- A ‘Youth Skills Development Project’ will run for three years. This project aims to equip marginalized young people with the knowledge and skills they need to empower themselves in AIDS care, support and management. It also aims to promote the integration of young people into existing community projects and health services and/or create new projects and health-care provision within communities. Target groups for this project are: young people aged 17 to 26 years; young people who are unemployed and not in school; members of youth and other organizations; and young people coming from the townships Mamelodi and Atteridgeville, and from Pretoria Central.
- The university is now seeking ways to address the care-related needs of staff and students through the expansion of the clinic services, provision of respite care and, possibly, the establishment of hospice facilities. There is also an extensive nutrition-support programme for students.
- A home-based-care kit has been developed, with the intention of improving the quality of life and care for people with a chronic illness, including AIDS, and contributing to effective symptomatic management in the home.
- A training programme is provided to academic and non-academic staff, students from all faculties, in addition to corporate training on peer education models, counselling and support, and workplace policy. Once they have undergone initial training, student volunteers can undergo further training within focal areas, such as education/awareness, media/resources, research, community outreach, workplace and ‘befrienders’. Students in the latter group undergo intensive counselling training.
- Community outreach has been set up, with AIDS centres at three satellite campuses of the university that are situated in rural areas.

### **Reported outcomes**

- The introduction of AIDS-related concerns into elements of the higher education curriculum, including in subjects such as law, agriculture and engineering, has led to greater understanding of the issues, de-stigmatizing and more open discussion of AIDS-related matters.
- The high-level support from the senior management has meant that AIDS is regarded as an essential aspect of all university decision- and policy-making.
- The high visibility of the programme and the work of the GIPA placements have contributed significantly to a change in the attitudes of staff and students, and are helping to create an environment in which addressing AIDS is recognized as integral to the work of the university. Many structures are changing in creative ways to accommodate the needs of staff and students living with HIV.

- The CSA's work addressing stigma and prejudice is benefiting the campus overall, allowing for effective education and campaigns.
- The numbers of students involved in the training have grown dramatically and there is now a strong core of student trainers and counsellors.
- The pilot project for the home-based-care kit have shown that the use of the kits in homes is having a profound effect on the way care of people living with HIV is understood and provided, on the quality of life of the person receiving care, and on the ability of families to care for people in resource-poor settings.
- An AIDS and Human Rights Research Unit has been established. This is headed by a Professor of AIDS and Human Rights, and encourages research in a wide range of fields, including sexuality and sexual rights; access to treatment; trade and international economic issues; and social and economic rights in relation to AIDS.

**Approach: Mobilizing community leaders to encourage greater openness around sexuality- and HIV-related issues within communities by building on positive social norms**

Project name and location

***Zambia Integrated Health Programme (ZIHP), Zambia***

**Background**

The Zambia Integrated Health Programme (ZIHP) is a technical assistance programme running from 1999 to 2004 that was jointly designed by the Ministry of Health and USAID in the context of decentralization of the health system. Assistance to the health sector is provided at different levels and follows an integrated approach. Topics addressed include AIDS, malaria, integrated reproductive health, and child health and nutrition. ZIHP has a geographical focus on 12 of 72 districts and has a nationwide focus primarily directed at (but not limited to) developing systems and mass-media interventions. A key aim has been to help the health sector test new methodologies and identify successful strategies to achieve health impact at community level, with a view to scaling these up countrywide.

The project provides technical assistance on:

- communication and behavioural change;
- community partnerships;
- improved health worker performance;
- nongovernmental organization strengthening; and
- private sector partnerships and systems support.

Key audiences include the entire community: women, children and men. Specific to AIDS, the project's aim is to increase the practice of behaviours and the utilization of services known to be effective in preventing the spread of HIV.

**Goals and objectives**

The overall aim of ZIHP is to contribute to the Government of Zambia's mission of providing high-quality and accessible health care to Zambians by:

- increasing the capacity of recipients to implement, monitor and evaluate health interventions;
- increasing the quality and coverage of health interventions in the participating districts;
- increasing the capacity of district health management teams to serve and respond to the needs of hard-to-reach communities; and
- increasing recipients' abilities to participate in health programmes.

**Key players**

ZIHP works with the Central Board of Health, MoH district health management teams, health centres and communities, and other local and international organizations. Each component of ZIHP's work is implemented in partnership with other organizations, as follows.

- The communications and community partnership component is implemented by the Johns Hopkins University/Centre for Communications Programs (JHU/CCP).
- Service delivery and nongovernmental organization strengthening is implemented by John Snow, Inc.
- Policy- and system-strengthening is implemented by Abt Associates.
- The social marketing component of ZIHP is implemented by the Society for Family Health and Population Services International.

### **Actions taken**

- Community members have specific functions locally. Some community members hold power in specific matters. These individuals include chiefs, traditional healers, teachers, and heads of government departments. Communities have norms that are culturally respected and shared, and people's actions occur within cultural contexts. Those in leadership positions can play a key role in encouraging behavioural change. Based on this, important HIV-prevention strategies include promoting behavioural change through the use of community-centred and interpersonal approaches, and supporting investments in advocacy and leadership development for influential community members. So far as stigma and discrimination are concerned, two approaches are being taken: building facilitation skills among key people to encourage more open discussion about AIDS, gender and sexuality; and supporting voluntary counselling and testing initiatives.
  - ❖ Teachers, school heads and officials from the district education office have been trained as advocates for the reduction of youth sexual-health-related stigma and discrimination in schools.
  - ❖ Training of middle management staff in the Judiciary Department has been undertaken to influence policy and reduce stigma, discrimination and marginalization of women and young people during the interpretation of local culture and tradition in the courts.
  - ❖ Training of district heads of government and private sector departments in selected districts has been carried out to lead and strengthen HIV responses in the workplace. At the same time, employment-based agents have aimed to facilitate ongoing dialogue around stigmatizing practices.
  - ❖ Community HIV educators have been trained in four districts as facilitators in this ongoing dialogue.
  - ❖ Training of 21% of traditional healers in the target districts has been undertaken to increase dialogue about AIDS. Traditional healers are influential people in communities and are key to reducing stigma and discrimination.
- Support has been provided to the HIV/AIDS Prevention and Care Project in Lundazi district, which provides mobile voluntary counselling and testing services at community level. The project runs a 'Know your status' voluntary counselling and testing campaign, and serves a population of 65 000.

## Reported outcomes

The outcomes to date reflect changes in perceptions, relationships and practices within target communities, as follows.

- Six out of 11 chiefs in Lundazi district have mobilized their communities to fight HIV- and AIDS-related stigma and discrimination. This is evidenced by the fact that more than 10% of community members have tested for HIV. Coupled with this are positive changes in some of the traditional practices that make women and girls vulnerable. Practices such as widow inheritance, ritual sexual cleansing and early marriages have been discouraged through a written decree. Three of the six chiefs have taken an HIV test and a female chief has shared her results with her subjects.
- Support groups have been formed by people who have taken an HIV test. These include community leaders, senior headmen, church leaders and advisers to the chiefs. Groups comprise both HIV-positive and HIV-negative individuals. A large number of the community support groups are managed by women against the background of a male-dominated society. They organize community meetings to discuss gender-related issues. Women are challenging male dominance in sexual relations and contribute to community discussions very assertively. “When we introduced the gender tools, we did have a problem but, after discussing with the men more, we found that they started accepting what we were trying to share with them,” says a programme officer, “Now we don’t have a lot of problems with men’s resistance. Women now are even coming on their own to collect the condoms on behalf of their husbands. That is quite a great change.”
- There has been increased demand for AIDS information and a willingness among communities to learn. Target communities are discussing gender and sexuality issues more openly and thus reducing the stigma that is associated with people’s sexual behaviour. Community meetings on gender, sexuality and AIDS are challenging traditional counselling messages given about girl-children, which emphasize the role of girls as sexual objects. Instead, traditional counsellors are encouraged to give more appropriate messages on sex and sexuality.
- In one district, churches have formed a coalition to support HIV prevention, care and support activities for people living with HIV and for young people.
- Traditional healers are beginning to change their perceptions of AIDS. The perception that a person gets HIV because they act contrary to community norms is now being replaced by facts. This approach puts AIDS in a more realistic perspective and results in greater respect towards community members who are living with HIV. Some traditional healers are members of home-based-care teams and distribute condoms. During education sessions, they emphasize issues of stigma and discrimination.
- Civic leaders in one district have an active programme on sexuality and AIDS, addressing stigma and discrimination on the local community radio once a week.
- In most schools, girls who become pregnant while at school are now given the chance to take leave and then return to continue their schooling.

## **Approach: Raising awareness through the media**

Project name and location

### ***Soul City, South Africa***<sup>25</sup>

#### **Background**

Soul City is a nongovernmental organization, a national multi-media ‘edu-tainment’ project that has been running since 1992. It aims to impact positively on people’s quality of life by integrating health and development issues into prime-time television and radio dramas in a mixture of South African languages. Soul City has developed and aired five television series of about 13 episodes each, in which a variety of topics has been addressed, including HIV and AIDS, tobacco, TB, youth sexuality, child health and violence against women. Soul City also has a number of offshoot projects including life skills materials and a children’s ‘edu-tainment’ TV series called *Soul Buddyz*.

All of the TV series have addressed issues relating to AIDS, including living positively, and AIDS-related stigma and discrimination. The radio series was developed largely to appeal to rural audiences and uses similar storylines and messages as the television. The storylines concerning AIDS were designed to make this an open issue, portraying it as an illness that can affect ordinary people, living ordinary lives in a typical township or rural area. One of Soul City’s goals has been to address stigma and to encourage support for people living with HIV.

#### **Goals and objectives**

To impact positively on people’s quality of life by integrating health and development issues into prime-time television and radio dramas, backed up by easy-to-read booklets.

#### **Key players**

Communities across South Africa—in particular, historically-disadvantaged groups. Soul City reaches 79% of its target population (16.2 million people).

#### **Actions taken**

- From the first series, broadcast in 1994, Soul City addressed topics related to AIDS. The second TV series (broadcast in 1996) dealt with living with HIV and AIDS and support groups, myths surrounding HIV transmission, the reaction of people who are uninformed to people living with HIV, dealing with being HIV-positive, and AIDS and death. The third TV series emphasized that people living with HIV have choices and can choose to live positively. It also emphasized the rights of people living with HIV. The fourth TV series of Soul City (broadcast in 1999) contained two episodes dealing with AIDS-related stigma and discrimination—one on discrimination in the workplace, and one on revealing an HIV-positive status and others’ reactions to it. Related themes in the fifth series (broadcast in 2000) included an episode on HIV-related death and living positively with HIV, one on the support and care of people living with HIV and community action to help in this, and another episode on prejudices about AIDS, the need for people to be informed and educated about it, and the importance of living positively.

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<sup>25</sup> <http://www.soulcity.org.za>

- In a parallel TV series targeting children, *Soul Buddyz 1* (26 half-hour episodes, broadcast in 2000), five episodes addressed people's reactions and prejudices to people living with HIV.
- A series of 15-minute daily radio broadcasts following storylines similar to those of the TV series has been developed.
- Soul City has produced a series of booklets, including those on *AIDS in our community* and *Living Positively with HIV/AIDS*. Youth education material aimed at the 12 to 18 age group includes *Choose Life: Living with HIV and AIDS*. Also available is a guide on how to design and manage an 'edu-tainment' project for social development. *Soul Buddyz* has materials aimed at children, containing facts about AIDS, as well as how to support people living with HIV, and with a chapter specifically on discrimination.

### Reported outcomes:

- An internal evaluation<sup>26</sup> of the second series revealed that, overall, attitudes towards people living with HIV have improved as a result of exposure to Soul City, and levels of uncertainty have been dramatically reduced. This was particularly striking among the younger age groups. Soul City gave the audience knowledge about the disease, enabling them to have informed opinions.

Findings of the evaluation of the fourth series<sup>27</sup> included the following.

- In terms of attitudes towards people living with HIV, the greatest quantitatively observable change was not in individuals' own attitudes, but in their perception of others' attitudes. That is, the perceived social norm regarding whether people living with HIV should be avoided and/or moved away, changed significantly towards a more tolerant position. Both Soul City TV and radio had a significant impact on the perception of this social norm, and the more exposure a person has had to Soul City, the greater the shift towards greater tolerance.
- Prominent themes emerging from the qualitative research on Soul City's impact on AIDS were: 1) accounts of personal attitudes and values shifting towards greater acceptance, inclusion, support and normalization of people living with HIV; and 2) awareness of the fact that one can live a normal, healthy life as an HIV-positive person.
- Soul City was significantly associated with people's professed willingness to perform the following acts, which could lead to safer sexual practices or greater acceptance of, and care for, people living with HIV: phone the AIDS helpline; help someone who is HIV-positive; ask partners to use condoms; and go for an HIV test. There was, however, less apparent impact on actual reported behaviour regarding these actions.
- Soul City was significantly associated with promoting interpersonal communication about HIV and creating greater openness and willingness around talking about sensitive subjects, including youth sexuality.

Soul City helps to create an enabling environment with respect to AIDS. In particular, there is evidence that Soul City has had a positive impact on community leadership

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<sup>26</sup> Available at: <http://www.soulcity.org.za/14.04.asp>.

<sup>27</sup> Available at: <http://www.soulcity.org.za/14.04.asp>.

(e.g., traditional and religious leaders, and local councillors) and service-providing institutions (e.g., health and education services, as well as the community-based organizations and nongovernmental organizations sector). Soul City is recognized as a relevant educational vehicle in terms of AIDS by these organizations and institutions, and people in these leadership roles or support positions are themselves influenced by Soul City, and actively use Soul City messages during the course of their community involvement. Thus, Soul City messages are effectively actively ‘amplified’ through community-based vehicles, structures, services and larger community forums.

- The *Soul Buddyz* evaluation<sup>28</sup> found that *Soul Buddyz* reached 67% of children aged between eight and twelve. Of children who had watched the series on TV, 77% said that they talked about the things they had seen on *Soul Buddyz* with other people. Of children who had TV but had not watched *Soul Buddyz*, 48% were willing to be friends with someone who had HIV, while 80% of those with high exposure to *Soul Buddyz* on TV were willing to be friends with someone living with HIV.

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<sup>28</sup> Available at: <http://www.soulcity.org.za/14.04.asp>.

## Antidiscrimination measures

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### **Approach: Mobilizing the private sector to implement non-discriminatory AIDS policies and promote understanding about AIDS**

Project name and location

### ***Thailand Business Coalition on AIDS (TBCA), Thailand<sup>29</sup>***

#### **Background**

The Thailand Business Coalition on AIDS (TBCA) is a non-profit organization established in 1993 to bring together businesses across the country to mobilize the private sector to respond effectively to the problems posed by AIDS, and to help tackle the discrimination faced by employees living with HIV. Established with support from the Thailand Ministry of Public Health, the World Health Organization, and the business sector in Bangkok, TBCA's basic approach has been to view AIDS as a management issue that must and can be managed in order to prevent further losses of valuable resources, such as human capital and expertise.

In 1997 and 2001, TBCA carried out surveys among 404 and 125 Thai companies respectively. These revealed that discrimination was rife, with many companies randomly breaching employees' rights to confidentiality by conducting mandatory pre-employment and on-the-job HIV testing, and most failing to provide staff with an understanding of AIDS through training programmes.

#### **Goals and objectives**

To mobilize the business community to respond effectively to the problems posed by AIDS by promoting coherent, non-discriminatory workplace policies and education programmes.

#### **Key players**

TBCA partners with both multinational and national companies, covering all major economic sectors, such as the manufacturing, hospitality, banking and pharmaceutical sectors. Companies range in size from as few as seven to more than 10 000 workers. While TBCA's membership was at first largely international, over time greater interest from Thai-owned and -managed companies has given it more of a local face. Today, about 43% of the firms are local. Other important partners include international chambers of commerce, as well as the Global Business Coalition on HIV/AIDS and the World Economic Forum Global Health Initiative.

#### **Actions taken**

- TBCA is the founder of the Asian Business Coalition on AIDS (ABC on AIDS), a network of nongovernmental organizations and businesses in 11 countries in Asia that aims to increase the business response to AIDS on a regional level. Two main strategies are pursued: 1) capacity-building of business partners, such as local nongovernmental organizations and other business coalitions on AIDS; and 2) international outreach

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<sup>29</sup> <http://www.abconids.org>

to businesses to implement HIV workplace programmes in Asia. ABC on AIDS coordinates the implementation of policies and intervention strategies and assists companies with information through its website [www.abcon aids.org](http://www.abcon aids.org).

- The ABC on AIDS website offers many resources, including a booklet identifying strategies for a business response inside and outside the workplace; a manual giving a comprehensive overview of AIDS-related interventions in the workplace; case studies of workplace programmes; a directory of AIDS organizations in the region; sample AIDS policies and guidelines for writing them; advice relating to reasonable accommodations for HIV-positive employees in order to assist them in staying in employment for as long as possible; information about testing and the importance of non-discrimination and the protection of human rights; advice about problem-solving in the workplace; and an outline of training programmes designed to prevent discrimination in the workplace.
- TBCA provides businesses with six training curricula that aim to prevent and control HIV in the workplace. Services include: executive briefing (senior management advocacy); human resource management training; staff training on HIV prevention and working together with HIV-positive people; peer education; training of counselors; and training of trainers.
- TBCA manages several community-based programmes to assist former employees living with HIV and to provide care and counselling services to those in need. As part of this work, TBCA operates an automated telephone service (1645 AIDS Hotline).
- TBCA provides ongoing consultation services to business on policy development, legal issues, and access to care and support. TBCA has developed and disseminated a manual on AIDS in the workplace as a resource for managers.
- TBCA organizes professional attachment programmes for business and non-business representatives on HIV workplace intervention strategies and private sector advocacy.
- TBCA designs and implements HIV intervention projects that target specific industries, such as the fishing industry (its 'Seafarers Programme' is conducted in partnership with UNICEF and the Ministry of Labour) and the insurance industry. TBCA has helped to set up an accreditation scheme that provides companies that work together with American International Assurance (AIA) with a financial bonus based on the implementation of HIV-prevention-and-control activities in the workplace.
- TBCA also provides in-house employee training in the form of tailored HIV-prevention-and-education programmes. This includes training in basic counselling and other skills so that employees can continue running AIDS programmes in their workplaces.
- In the coming five years, with support from the Global Fund for AIDS, TB and Malaria, TBCA, the Ministry of Public Health, the Ministry of Labour and 34 collaborating nongovernmental organizations will work together on a project titled: 'HIV/ AIDS Prevention and Management in the Workplace'.

## Reported outcomes

- Formal AIDS workplace policies have been produced by partner companies. Policy issues include: non-discriminatory measures, confidentiality of HIV status (no HIV testing), employees' access to accurate information on AIDS through training and awareness-raising, and access to care and support.
- Staff and management training programmes have been implemented on an annual basis.
- Workplace programmes have been expanded to include other companies and/or industries through utilization of peer influence networks and advocacy on a nation-wide basis.
- Assistance has been provided to former employees and dependents living with HIV, which has helped to improve their quality of life.
- Advocacy among government departments, chambers of commerce and professional organizations has raised awareness of AIDS workplace programmes.
- Employees have volunteered to participate in and assist AIDS nongovernmental organizations or specific AIDS projects.
- HIV-positive employees have reported increased levels of acceptance and support received in relation to their seropositive status.
- Since the creation of the automated telephone hotline in 2000, more than 80 000 calls have been received from all over Thailand.
- Pilot programmes promoting non-discrimination and enforcement of the human rights of employees living with HIV have been established in other Asian countries, with assistance from TBCA.

## **Approach: Improving employee quality of life through access to integrated care and the implementation of non-discriminatory policies**

Project name and location

### ***Volkswagen (VW) Brasil***

#### **Background**

*Volkswagen do Brasil* is a subsidiary company of the Volkswagen Group, the fourth-largest automobile manufacturer in the world, and has 30 000 employees. *VW do Brasil's* AIDS Care programme was initiated in 1996—an initiative focusing on HIV prevention and the care and treatment of employees living with HIV. In the decade preceding this, there were 115 known cases of HIV infection among employees and, among this group, there was a high incidence of HIV-related illness, a high cost of care with repeated hospital admissions, and high rates of withdrawal from work.

From a business perspective, the experience of *VW do Brasil* provides evidence of the effectiveness and costs savings to companies initiating coordinated and specialized treatment and care to its workforce. The savings from reduced absenteeism and loss of employees are central to this approach. Following the decision by the Brazilian Government to provide treatment for all HIV-positive Brazilians in August 2000, the cost of this AIDS care programme fell dramatically.

#### **Goals and objectives**

To institute an AIDS care programme that creates an effective and efficient service for employees and prevent costs related to AIDS escalating; to promote anti-discriminatory policies with respect to employees living with HIV; and to run a parallel HIV-prevention programme.

#### **Key players**

VW employees, management, health services.

#### **Actions taken**

- The prevention programme in the workplace focuses on information, education and counselling, using educational presentations and videos, information dissemination via the company radio, internal newspapers and intranet, bulletin boards and AIDS brochures. Condom machines have been installed on works premises. VW staff members participate in activities organised by the National Business Board for the Prevention of HIV/AIDS, of which VW is a member.
- The care programme for people living with HIV began with the development of a Technical Protocol, which has sought to standardise the care and assistance provided

within the programme, while allowing a degree of flexibility for individuals' needs. Treatment and counselling is provided, which includes access to infectious disease specialists, social workers, nutritionists, psychologists, and provides referrals to specialized hospitals and agencies providing home-based care. People living with HIV are given access to antiretroviral drugs and clinical tests such as CD4/CD8 counts and viral load measures.

- As part of the company's non-discrimination policy, assistance is given to employees living with HIV in order to reintegrate them into the workplace. Antidiscrimination measures include the prohibition of mandatory HIV testing, no dismissal of employees who are HIV-positive, and the right to confidentiality of employees living with HIV.

### **Reported outcomes**

- By the end of 2002, the company was reporting that since the initiation of the care programme its monitoring system had shown a 90% reduction in hospitalizations, 40% reduction of costs of treatments and care. In addition, 90% of people living with HIV were active.
- Improved quality of life for people living with HIV within the workplace was noted, as well as a perceived increase in the level of employee satisfaction with the company.
- There has been a reduction in the periods of absence from work due to the prevention and control of HIV-related illnesses.

## **Approach: Improving clinical care for patients living with HIV through participatory activities with health care managers and providers**

Project name and location

### ***Improving the hospital environment for HIV-positive clients in India***<sup>30</sup>

#### **Background**

Previous studies conducted in India have shown that, as elsewhere, attitudes of hospital staff towards people living with HIV are influenced by fears and misconceptions about HIV transmission, and that there is inadequate awareness and practice of procedures to ensure staff safety. The high levels of stigma and discrimination experienced by people living with HIV in care-giving contexts can be attributed not only to prejudice among health care workers, but also to a shortage in supplies and training needed for infection control. In order to address these issues, the Horizons Project and SHARAN (Society for Service to Urban Poverty) have been testing innovative approaches for creating ‘patient-friendly’ hospitals in collaboration with three New Delhi hospitals.

#### **Goals and objectives**

To improve hospital-based services for people living with HIV in New Delhi

#### **Key players**

Participating hospitals, the Horizons Project, SHARAN, people living with HIV, health care workers, and the National AIDS Control Organization of India (NACO).

#### **Actions taken**

- Research was first undertaken to identify the strengths and limitations of services for people living with HIV in three hospitals in New Delhi. The project team interviewed health-care workers, medical superintendents, and patients and their caregivers to explore manifestations and causes of stigma and discrimination in clinical settings, and to develop a framework and indicators for designing and evaluating the intervention. This was followed by baseline research during which the researchers observed hospital practices, documented policies and conducted a survey among doctors, nurses, ward staff (ward boys and sweepers) and patients (n=884). In addition, focus group discussions and interviews were conducted with HIV-positive individuals and their caregivers.

Researchers found that people living with HIV and their caregivers reported receiving differential and discriminatory treatment from health-care workers. This limited their access to care and included isolation in wards, early discharge from hospital, delays in surgery, and serious breaches of confidentiality—all effectively limiting access to care. There were few links to community-based care and support services. The study team also found that, within the health-care setting, misconceptions about HIV transmission, negative and judgemental attitudes towards people living with HIV, inadequate training and supplies for infection control, and lack of institutional policies on confidentiality and HIV testing all contributed to inequality in treatment.

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<sup>30</sup> Mahendra V., George B. and Gilborn L. (2002) *Reducing stigma by promoting PLHA-friendly hospitals*. XIV International AIDS Conference, Barcelona, Spain, July 2002.

- Based on these findings, the project team designed a tool called ‘The Patient/PLHA-friendly Achievement Checklist’<sup>31</sup>. This helps managers to identify how well their facility reaches, serves and treats HIV-positive people, in particular institutional strengths and weaknesses, and assists them in setting goals for the improvement of services for people living with HIV.

The checklist is designed in a simple format that can be readily adapted for each unique context. It can be used by individual managers or groups of managers and/or staff, and can be applied to large hospitals, clinics or specific departments. Users of the checklist can use hospital records, survey data, observation or simply ‘guesstimates’ to rate their own institution.

To develop the checklist, ‘gold standards’ were compiled from national and international guidelines and policies on the human rights of people living with HIV, HIV testing and counselling, infection control, and care and management of AIDS. These standards were reviewed and endorsed by the National AIDS Control Organization (NACO) and by hospitals participating in the study through a series of consultative discussions. They were then adapted into a checklist format. The checklist has the following sections.

1. Access to care services.
2. Testing and counselling.
3. Confidentiality.
4. Infection control.
5. Quality of care.

Within each of these domains, there are four subdomains:

- Practice (practices and behaviours of staff);
- Training (building and maintaining the capacity of staff to practice these standards);
- Quality assurance (institutional mechanisms to monitor and ensure practice of gold standards); and
- Policy (institutional rules and regulations stipulating or enforcing the gold standards).

In each of these subdomains, there are between one and five checklist items in the form of simple ‘true/false’ statements that represent gold standards.

- Using a participatory process that has included discussion of the baseline data and the self-assessment tools, managers at each hospital worked with the project team to draft an action plan to improve services for people living with HIV and working conditions for staff. The checklist has enabled hospital managers to develop and set priorities for activities to address the gaps identified. Action plans vary by hospital, but include such actions as developing and posting materials with clear visual imagery on universal precautions to reach all staff, training designated health-care workers from each hospital in pre-and post-test HIV counselling, and offering staff participatory sensitization training, designed and implemented by local AIDS organizations. Hospital managers were also engaged in developing policy guidelines for AIDS care and management that were then widely disseminated to staff.

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<sup>31</sup> Patient/PLHA-friendly Achievement Checklist – a self assessment tool for hospitals and institutions caring for people living with HIV and AIDS. See: [www.popcouncil.org/horizons/pfechklist.html](http://www.popcouncil.org/horizons/pfechklist.html).

- The interactive training module has been piloted to sensitize health-care workers on various issues related to AIDS. The objectives are:
- to improve knowledge on the basics of HIV transmission and procedures for infection control in order to allay health-care workers' fears and misconceptions;
- to introduce concepts of confidentiality, patient rights, voluntary counselling and testing, and social care and support to sensitize health-care workers to the needs and rights of people living with HIV;
- to change the negative attitudes of health-care workers in order to ensure the provision of humane and equitable care and treatment; and
- to test the feasibility and effectiveness of implementing an innovative participatory training module among a group of health-care workers.

### Reported outcomes

- The checklist enabled managers of health facilities to engage in participatory problem identification and recognize issues of stigma, discrimination and quality of care when, initially, they had been reluctant to acknowledge the existence of problems in these areas.
- By developing solutions through producing an action plan tailored to their particular setting, hospitals are actively cooperating and appear to feel a sense of ownership of the project.
- Reported outcomes following the piloting of the interactive training module include positive changes in attitudes and behaviours in all categories of health-care workers immediately after training. After a two-month follow-up, attitudes among doctors continued to show an improvement, whereas those of nurses and ward staff showed a slight decline<sup>32</sup>.
- Post-intervention, a follow-up survey (N=885) and checklist scores were used to measure progress towards 'patient/PLHA-friendly' hospital environments. Overall, significant improvements in health workers' knowledge, attitudes and practices were recorded. Some examples of this are described below, based on a comparison of pre- and post-intervention data compiled from all three intervention hospitals<sup>33</sup>.
  - ❖ Knowledge about HIV transmission and prevention increased considerably, especially among ward staff. More ward staff know that HIV cannot be transmitted by sharing utensils with people living with HIV (67% at baseline versus 83% at endline), touching someone with AIDS (81% versus 96%), and sharing clothes with a person living with HIV (63% versus 86%).
  - ❖ Attitudinal improvements were seen in all health care workers with respect to general perceptions of people living with HIV, as well as issues related to caring for them in clinical settings. More health workers disagreed with the statement that HIV spreads due to immoral behaviour (29% versus 51%), more stated that they

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<sup>32</sup> George B., Jadhav S., Mahendra VS., Mudoi R., Gilborn L. and Samson, L. (2002) *Implementing a participatory and interactive training module to sensitise health care workers on HIV/AIDS issues: experiences from India*. XIV International AIDS Conference, Barcelona, Spain, July 2002.

<sup>33</sup> Mahendra VS., Gilborn L., Mudoi R., Jadav S., Gupta I., Bharat S., Prasad R., Upadhyay D. and Raman, V. (2004) *Making hospitals more PLHA-friendly :findings from operations research in New Delhi, India* 132<sup>nd</sup> Annual Meeting of the American Public Health Association (APHA), Washington. DC. November 2004.

would be willing to share a meal with someone with AIDS (42% versus 72%), buy food from a foodseller with AIDS (54% versus 88%), and move into a home next to a neighbour with AIDS (73% versus 94%). In relation to clinical care, there was an increase in the proportion of health workers who disagreed with discriminatory statements, such as ‘HIV-positive patients should be kept at a distance from other patients’ (44% versus 57%) and ‘clothes and linen of HIV positive patients should be burned or disposed’ (32% versus 46%).

- ❖ Greater understanding and better practice in relation to voluntary counselling and testing procedures, infection control measures and confidentiality were observed. More doctors agreed that a patient’s blood should never be tested without consent (39% versus 67%), and more sought informed consent the last time they ordered an HIV test (40% versus 59%). In addition, more doctors reported having arranged pre-test counselling for patients who had received an HIV test (31% versus 46%). There was an increase in health workers reporting glove use for at-risk procedures as well as awareness of how to access post-exposure prophylaxis. There were also significantly fewer hospital staff reporting lack of supplies for universal precautions and infection control after the intervention. Significantly fewer doctors (51% versus 29%) reported informing ward staff in the hospitals about HIV-positive patients admitted in the department, as well as fewer nurses (43% versus 28%) reporting segregation of HIV-positive patients from other patients.
- Despite the positive outcomes, there were some areas that require attention for improvement. While health workers exhibited increased respect for the importance of informed consent, they also continued to support the need for widespread testing and sharing of information about patient’s HIV-status. In addition, even though there was an overall improvement in knowledge regarding HIV transmission and prevention, some misinformation persisted.

## Conclusions

Participatory methods, access to facility-specific data and the checklist served as critical tools in mobilizing hospital managers to take actions to make hospitals ‘Patient/PLHA-friendly’. In addition, the adoption of a collaborative approach by government, non-profit groups and researchers was effective in contributing to the reduction of stigma and discrimination in the hospitals. Furthermore, the attempt to effect change in each setting was not top-down, but involved all levels of health workers, from ward staff to hospital managers and administrators. At the same time, there is need for further research to determine whether the improvements reflect actual reductions in stigma and discrimination as perceived by people living with HIV, and whether they will be sustained over time.

## Human rights and legal approaches

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**Approach: Promoting the human rights of people living with HIV and providing redress for violations of their human rights**

Project name and location

***Acción Ciudadana Contra el Sida: Citizens' Action against AIDS (ACCSI), Venezuela***

### **Background**

ACCSI is a non-profit organization established in 1987 in recognition of the frequent violations of the human rights of people living with HIV. It provides free legal assistance to people living with HIV and to their families. Lawyers act in cases and appeals such as in the areas of employment discrimination, medical malpractice or social service problems. ACCSI works closely with relevant sectors including government departments, AIDS community groups, human rights organizations and the private sector.

### **Goals and objectives**

To promote and protect the human rights of people living with HIV and other vulnerable people.

### **Key players**

People living with HIV and their families, government departments, AIDS and human rights organizations.

### **Actions taken**

- Education regarding human rights and the prevention of HIV.
- Defence of the human rights of people living with HIV and other vulnerable people through legal action. Legal advice is also provided to people living with HIV, their families and their associates.
- Provision of advice to the private and public sector on workplace and social security matters relevant to AIDS.
- Research on subjects related to human rights, sexual and reproductive health and ethics.
- In 1994, ACCSI played a key role in lobbying for a Ministry of Health and Social Assistance resolution to regulate the use of HIV testing. The resolution aimed to reduce discrimination in the workplace, in hospitals and medical centres, and in educational institutions. The group has also participated in law reform commissions with respect to the National Health Law and the Protections against Venereal Disease Law.
- Encouragement of the greater involvement of people living with or affected by AIDS (GIPA).
- Maintenance of a resource centre.

With respect to the above, and as a first step to legal action, ACCSI identified which services were available to people with HIV and found that treatment access was limited. Only 30% of the workforce in Venezuela was covered by the social security system. Although the system did provide some medication for people living with HIV, services were deficient and the medication supplied in an irregular manner. The public health system provided some assistance programmes and hospital services, but supplied no antiretroviral treatment, no pertinent medical tests, and no treatment for opportunistic infections (with the exception of TB).

To challenge the very limited treatment access of people living with HIV, ACCSI launched a series of lawsuits against the Ministries of Health, Defence and Social Security on behalf of several individuals living with HIV. ACCSI decided to focus its attention initially on the social security system as the area most likely to produce results. In 1997, ACCSI, together with a number of health professionals, lawyers and AIDS activists, filed a lawsuit on behalf of 11 people living with HIV. The lawsuit alleged that the claimants were not receiving proper medical attention. The lawsuit was based on the rights of people living with HIV 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, the International Pact on Economic, Social and Cultural Rights, and other conventions signed and ratified by Venezuela. The lawsuit also made reference to the Universal Declaration of Human Rights.

Five additional lawsuits followed. Encouraged by the success of the court actions against the social security system, ACCSI filed a lawsuit against the Ministry of Defence on behalf of four soldiers living with HIV in the National Armed Forces who were discharged when found to be HIV-positive. The lawsuit said that the soldiers had a right to antiretroviral therapies and adequate medical attention, at least during the period of obligatory service. This lawsuit was also based on principles enshrined in the national constitution and international treaties.

### Reported outcomes

- Legal action by ACCSI over a number of years has resulted in the courts ordering the government to provide treatments for all people living with HIV in Venezuela. This has happened in stages. By August 1998, the social security system had established a programme of care and treatment for 2200 people living with HIV. Lawsuits filed against the Ministry of Health resulted in an additional 1500 women, children and men receiving antiretroviral therapies. In January 1998, the court ruled in favour of the four military claimants and ordered the Ministry of Defence to provide them with antiretroviral therapies and full medical services. The ruling obligated the Ministry of Defence to provide the patients with confidential care and pensions. The verdict in favour of the four members of the military established that HIV-positive individuals had the right to work, privacy, non-discrimination, dignity and psychological and economic attention, as well as health care. As a result, the Armed Forces are providing appropriate medical care to soldiers living with HIV during their obligatory service.
- Up to this point, all the court rulings had applied only to the individual claimants named in the lawsuits. However, in July 1999, the Supreme Court ordered the Ministry of Health to provide, free of charge, antiretroviral medications, treatments for opportunistic infections and diagnostic testing to *all* Venezuelan citizens and foreigners resident in Venezuela who are living with HIV. This was the first time the Court had ruled in the collective interest. The Supreme Court said that the right to health and

the right to life were closely linked in this case to the right to access the benefits from science and technology. It cited recent developments in antiretroviral therapy as examples of the achievements of science and technology; and it said that these developments allow people living with HIV to prolong their lives and to improve their quality of life. To guarantee the implementation of court rulings, ACCSI established committees of people living with HIV who volunteered to observe and facilitate the process between Ministries, people living with HIV, and the pharmaceutical industry, and to help ensure adequate supplies. Despite challenges relating to insufficient budgets and supply failures, the programme is assisting approximately 15 000 people living with HIV.



Project name and location

## ***AIDS Law Unit, Legal Assistance Centre, Namibia***

### **Background**

The AIDS Law Unit is part of the Legal Assistance Centre, which has a head office in Windhoek and two regional advice offices. This is a non-profit public interest law centre set up in 1988, whose aim is to protect the human rights of all Namibians by working in three broad areas: litigation and advice, education and training, and research and advocacy. The centre seeks to give effective content to basic constitutional civil and political rights, as well as advancing Namibia's socioeconomic development goals.

### **Goals and objectives**

The overall objective of the AIDS Law Unit is to promote a human rights based response to AIDS in Namibia. The Unit addresses discrimination issues on the basis of HIV-positive status and provides an avenue for redress for people living with HIV who have been discriminated against on the basis of their seropositive status.

### **Key players**

People living with and affected by HIV; public and private employment sectors.

### **Actions taken**

- A free legal advice and litigation service is provided for people living with or affected by AIDS. The unit has handled several cases relating to discrimination on the basis of HIV-positive status in respect of access to employment and to insurance. It also runs a legal advice clinic for people living with and affected by HIV. The issues handled include the drafting of wills, maintenance and social security claims, insurance, and unprofessional conduct on the part of medical practitioners. The clinic also serves as a referral agency for problems that are not of a legal nature.
- The Unit conducts research into existing and emerging discrimination issues, as well as into appropriate policy and legal responses. For example, the unit has conducted a survey on how people living with HIV are treated in the employment sector in Namibia. One of the survey's aims was to determine the effect of the government's *Guidelines for the Implementation of a National Code on HIV/AIDS in Employment* on the national working environment.
- Appropriate policies and legislation are formulated to address issues of discrimination on the basis of HIV-positive status. The unit provides assistance to employers and trade unions in developing appropriate workplace AIDS policies. In 1999, for example, the unit coordinated a consultative process towards a policy on HIV/AIDS notification, reporting and confidentiality, which was commissioned by the Ministry of Health and Social Services.
- In 2000, the Unit worked with the Namibian Police to develop a policy on HIV and awaiting-trial prisoners. The Unit also coordinated a committee to draft a charter on the protection of human rights of people living with HIV in Namibia. The charter was launched at the end of 2000. In 2002, the Unit developed a policy on AIDS for the

education sector, commissioned by the Ministries of Education (Basic and Higher), and in 2004 finalized the national policy on orphans and other vulnerable children, commissioned by the Ministry of Women's Affairs and Child Welfare. The Unit is currently assisting the Office of the Prime Minister with the development of a HIV and AIDS Charter for the public service sector.

- The Unit runs programmes with people living with HIV to develop advocacy skills in nongovernmental and community-based organizations representing such people. It also engages in advocacy and lobbying on issues relating to stigma and discrimination, and lobbies government for appropriate legal reform.
- Appropriate education and training programmes and materials on AIDS and discrimination are designed and facilitated.
- In 2000, the Unit initiated a Treatment Access Forum, composed of doctors and representatives of the pharmaceutical sector, the National AIDS Coordination Programme, and AIDS Service Organizations to lobby for the provision of affordable treatment for all Namibians who need it.

### **Reported outcomes**

- The Unit successfully challenged the Namibian Defence Force's (NDF) policy of pre-employment testing and excluding people with HIV from employment. The Labour Court found in May 2000 that an employer such as the NDF is not permitted to exclude people from employment on the basis of their HIV-positive status, because such status does not necessarily mean that the infected person is unfit for employment.
- The Unit has contributed to the development of appropriate AIDS workplace policies in the public and private sectors, as well as to the national AIDS policy framework. It has successfully lobbied government for legal reform to address AIDS-related stigma and discrimination. For example, the legislature recently accepted the Unit's submissions in respect of the inclusion of HIV status as a prohibited ground for discrimination in the new Labour Bill.
- The Unit has produced a series of booklets on issues such as wills and inheritance, HIV and pregnancy, access to affordable treatment, and AIDS in the workplace.

Project name and location

## ***HIV/AIDS Unit, Lawyers' Collective, India***

### **Background**

The Lawyer's Collective is a non-profit organization based in India, which was established in 1981 to provide legal aid to marginalized groups in public interest litigation. The Collective is a public interest group of professional lawyers, law students and other law affiliates, whose aim is to meet the unmet legal needs of society and particularly the disadvantaged sections of society through legal aid, advice and public interest litigation. The public interest work in which the collective as a whole is engaged includes legal aid, advice and public interest litigation on the issues of women's rights, rights of the homeless and housing, environmental protection and promotion, health issues including AIDS, reproductive rights, and the rights of the unorganized sector of workers, particularly contract labourers.

In response to the AIDS epidemic, the Collective established a HIV and AIDS unit in Mumbai, with financial assistance from the European Commission. This provides legal aid, advice and allied services to people living with HIV.

### **Goals and objectives**

To protect and promote the fundamental rights of people affected by HIV, which have been denied in areas such as health care, housing, education, insurance, employment, dues relating to pensions, information and other services, rights to privacy and confidentiality, and marital rights relating to maintenance and custody.

### **Key players**

People living with HIV.

### **Actions taken**

- The HIV and AIDS Unit has initiated public interest litigation on the following public health issues: access to treatment and services; HIV testing; privacy and confidentiality; consent to testing; safe blood supplies; decriminalization of homosexuality; the protection of sex workers; discrimination in employment and services; and rights of HIV-positive women in the family and home, as well as outside these domains.
- The Unit has raised awareness through advocacy about the legal and ethical implications of the AIDS epidemic, including dialogue on law reform, training national networks of lawyers on AIDS issues, and conducting workshops on legal and ethical issues relating to AIDS for people living with HIV, the legal community, policy planners, activists, nongovernmental organizations, and other organizations working on AIDS-related concerns. The Collective has also raised public awareness about AIDS through public rallies, and mobilizes public opinion against stigma and discrimination by advocating for the rights of marginalized groups.

### **Reported outcomes**

- The HIV and AIDS Unit has successfully defended workers who have been discriminated against and lost their jobs on account of their HIV-positive status. One of its

most significant achievements in this area has been the upholding of the 'suppression of identity' clause. This allows a person living with HIV to file his or her case under a pseudonym. This is important, as people living with HIV are often reluctant to proceed with litigation for fear that their positive status will be disclosed to the public at large, and that they will suffer discrimination. The unit has also won a case relating to breach of confidentiality in which a hospital disclosed a patient's HIV-positive status to his employer.

- The Unit has won cases in the area of human rights of marginalized groups. The Mumbai sex workers case is a notable example. Based on a newspaper report to the effect that there were many under-age girls in the sex trade in Mumbai, many of whom were HIV-positive, an order was passed by the Bombay High Court directing the police to round them up. They were detained and placed in state protective homes. A large number of those who were rounded up were not under age and were therefore held without legal authority. By an order of the court, they were all tested for HIV without consent. The Lawyers' Collective then intervened and obtained an interim order for proper medical treatment of the persons and restraint from any HIV testing. A petition filed by the collective to release the sex workers who were over 18 was, however, dismissed.

## **Approach: Advocating increased access to HIV treatment**

Project name and location

### ***Treatment Action Campaign (TAC), South Africa***

#### **Background**

The Treatment Action Campaign (TAC) was launched on 10 December 1998—International Human Rights Day. It is a grassroots organization that works to raise public awareness and understanding of the issues that surround the availability, affordability, and use of HIV treatments. TAC is a vocal and visible lobby in the developing world for the rights of people with HIV to treatment, justice and non-discrimination.

The launch of TAC opened a new chapter in the struggle about AIDS in South Africa. It came at a time when many existing AIDS organizations were struggling with internal problems in the face of a growing epidemic. The public was largely disengaged. South Africans were tired of messages of doom and gloom. They were averse to hearing how AIDS was going to kill millions of people, wreck the economy and overwhelm the health services, and how there was nothing that could be done to stop it. Through its actions, TAC has aimed to change the nature of AIDS debate. TAC campaigns for greater access to treatment for all South Africans, by raising public awareness and understanding about issues surrounding the availability, affordability and use of treatments for HIV and AIDS. The organization mobilizes people living with HIV and AIDS to struggle for their rights.

#### **Goals and objectives**

TAC's foremost objective is to make essential medicines accessible to all people with HIV and AIDS; to highlight disparities and problems in access to treatment; to campaign for improvement in the affordability and quality of health-care access including treatment for all, with particular emphasis on HIV and AIDS; to highlight problems with South Africa's health-care infrastructure and campaign to have them eliminated; and to educate people living with HIV and AIDS, health-care workers especially nurses and the public about treating HIV and AIDS and working with antiretroviral drugs, and how to live more healthily with HIV and AIDS.

#### **Key players**

People living with HIV.

#### **Actions taken**

- TAC has promoted treatment awareness and treatment literacy through the provision of information. TAC maintains visibility for these issues through posters, pamphlets, meetings, street activism and letter-writing. It also organises workshops for doctors, nurses and others, and has distributed numerous posters, pamphlets, booklets and newspaper advertisements on treatment and prevention issues.
- TAC's Treatment Literacy Programme tackles dangerous myths related to transmission of HIV and the causes of AIDS, and provides communities with the essential knowledge about the disease that they need to enforce their rights. Treatment Literacy Practitioners (TLPs), work in communities, clinics, support groups, nongovernmental

organizations, community-based organizations, faith-based organizations, churches and TAC branches.

- TAC has lobbied pharmaceutical companies to lower the cost of all HIV and AIDS medications and maintains pressure on the government to fulfil its obligations to address HIV and AIDS.
- TAC has campaigned for AZT and Nevirapine to be made available to HIV-positive pregnant women in the public health-care system in order to prevent mother-to-child transmission of HIV. This has entailed successful legal action in the Constitutional Court, with a case founded on the rights to equality, dignity, reproductive autonomy, and access to health-care services, including reproductive health care.
- TAC has challenged AIDS-related stigma in communities by promoting the wearing of T-shirts emblazoned with the words HIV-positive (endorsed by Nelson Mandela, whose photo was printed on the T-shirts). The aim is to emphasize that AIDS is a shared concern, not just the problem of those who are infected.
- TAC has conducted extensive international work including sending the delegation to the International AIDS Conference in Thailand, which met with Kofi Annan and helped to set an agenda for worldwide treatment and prevention. Its senior members have spoken on many international platforms and have participated in a campaign for access to generic medicines.
- TAC has launched the TAC Treatment Programme (TAC TP), as an innovative model to provide comprehensive medical care and medicines to activists with AIDS, who are saving the lives of others, and to an equal number of people in the communities where they work.
- TAC co-hosted a high profile conference in July 2004, the People's Health Summit that focused on the health system and the challenges with implementation of the antiretroviral treatment rollout. The conference looked at major challenges remaining to improve the health service and recruit additional health workers, these included building meaningful involvement of communities with health services, and ensuring that national, provincial and local government comply with the constitutional obligations to provide all people in South Africa with access to health care services that respect their autonomy and dignity.

### **Reported outcomes**

- TAC has helped to create public awareness that treatment for HIV and AIDS exists and should be available to all, rich and poor alike. Before TAC began its efforts, most South Africans did not know that there was such treatment, believing that infection meant certain death. TAC insist that all people have a right to essential medicine and that a situation in which such drugs are beyond the reach of millions of poor people is simply unacceptable.
- A court judgement on 14 December 2001 ruled that a countrywide prevention of mother-to-child transmission programme is an obligation of the state. The government appealed and announced an inclusive national consultation on prevention of mother-to-child transmission. The Constitutional court hearing the appeal ordered

the government to remove restrictions that prevent Nevirapine from being made available to prevent mother-to-child transmission in public hospitals and clinics.

- TAC, in collaboration with *Médecins Sans Frontières*, has imported generic antiretroviral medicines from Brazil, including AZT, Lamivudine and Nevirapine. TAC continues to import generic fluconazole in defiance of Pfizer's patent. Many HIV-positive people have benefited from this.
- On 19 November 2003, the South African Cabinet approved the Operational Plan for Comprehensive Treatment and Care for HIV/AIDS. The decision was made possible by a five-year campaign of the Treatment Action Campaign, and its allies.
- TAC has worked productively with its partner organization, particularly the AIDS Law Project (ALP). TAC and ALP have worked together to ensure the formation of the Joint Civil Society Monitoring Forum which has now produced two reports on the rollout of the comprehensive operational plan.
- TAC has helped shift thinking from acquiescence in the unavailability of treatment to people in poor countries to a clear understanding that treatment is essential to prevention and care to human rights and, ultimately, to containing and defeating the epidemic.

## Discussion

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As discussed earlier, programmes that have addressed AIDS-related stigma and discrimination tend to have been of three broad types.

- *Stigma-reduction approaches*—frequently consisting of community-based HIV- and AIDS-prevention-and-care programmes, mobilizing a wide range of actors.
- *Specific antidiscrimination measures*—often focused initiatives in institutional settings, such as workplaces or health-care centres; and
- *Redress mechanisms*— using legal means to challenge discrimination against, and to seek redress and promote the human rights of, people living with HIV.

Importantly, and as we have seen, real-life programmes frequently use a combination of approaches, acting at one or more of these levels simultaneously. This is important in adding synergy or strength to work that is undertaken. It also enables a wide range of individuals to be involved—from counsellors and health-care workers, to lawyers, community workers and human rights activists. Broad-based multi-pronged strategies are central to success in combating the stigma and discrimination to which AIDS has given rise, and in promoting the rights of people living with HIV, their families and people vulnerable to HIV infection.

The case studies outlined above demonstrate that there are many potential entry points for the reduction of AIDS-related stigma and discrimination, and the promotion of the human rights of people living with HIV.

By looking closely at the work that has taken place, and by looking across projects and activities for common elements, it is possible to identify a number of key principles of success. Each of these offers an entry point for innovative and potentially effective work.

### Key entry points

#### 1. Promoting solidarity through integrated care

Home-based-care programmes offering integrated medical and social support to families and households affected by HIV can dramatically improve quality of life. Such programmes can reduce the emotional and physical suffering associated with HIV-related illness by enhancing families' interest in, and capacity for, caring for relatives living with HIV.

In addition to improving the quality of care given to affected individuals, home-based-care programmes may also help to reduce discrimination in their communities by bringing motivation for broader change in attitudes. Witnessing or experiencing caregiving can encourage shared responsibility by community leaders in acknowledging the reality AIDS. It can also change perceptions of what counts as a suitable response to HIV-affected people.

Recruiting and training local volunteers to assist in the provision of care may help to reinforce the message that AIDS is a shared concern. The demonstration of care and caring by trained volunteers, especially when combined with information-giving, can reinforce the message that close and sustained contact with people living with HIV does not pose any risk of infection. This may mitigate the stigma derived from people's fear of the transmissibility of HIV through everyday contact.

## **2. Promoting the greater involvement of people living with or affected by HIV (GIPA)**

The GIPA principle encourages the active involvement of people living with AIDS in policy-making, and in the development and implementation of programmes<sup>34</sup>. The active involvement of people living with HIV in prevention and care programmes has the potential to reduce AIDS-related stigma and discrimination. It can do this by promoting the empowerment of people living with HIV, and by strengthening the capacity of affected communities to accept affected individuals. More specifically, involving people living with HIV in prevention and care activities can:

- encourage greater community acceptance of people living with HIV by promoting a better understanding of their situations;
- reduce self-stigma by increasing the confidence of those living with HIV; and
- encourage further disclosures of a seropositive status by promoting openness and discussion around AIDS.

Activities such as training and supporting people living with HIV as public speakers, educators and counsellors have helped to reduce stigmatization. Training people living with HIV, for example, to deliver personal testimonials in participatory educational sessions can encourage others to place themselves in the position of someone who has suffered discrimination and appreciate the injustice of discriminatory actions. It may also have a positive impact on prevention efforts, by personalizing HIV risk. The ensuing realization that AIDS is a shared concern may lead to the reduced stigmatization of people living with HIV.

In addition to promoting a better understanding of the circumstances of affected people, increasing the visibility and integration of people living with HIV into community-based programmes can further reduce stigmatization by implicitly reinforcing the message that people living with HIV have the potential to lead productive lives and contribute constructively to their communities. This involvement can also help to reduce self-stigmatization, by building the confidence of people living with HIV, and by reducing their feelings of isolation and powerlessness<sup>35</sup>. This is particularly the case where affected individuals are supported by associations of people living with HIV to participate in income-generating and skill-development activities.

## **3. Mobilization of community leaders and, in particular, religious leaders in prevention and care**

Leadership and faith form an important part of most people's lives, and religion plays an important role in influencing identities, practices and moral positions. Because religious leaders are often highly respected, they have an important role to play in challenging AIDS-related stigma and discrimination. While religious organizations have sometimes reinforced stigma by too readily associating AIDS with religious teachings about 'sin', there are notable examples where they have worked to foster tolerance and social solidarity using approaches that are non-judgemental and not based on fear.

Programmes that have challenged stigma and discrimination have mobilized religious leadership in the following two related ways.

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<sup>34</sup> UNAIDS (1999) *From principle to practice: greater involvement of people living with or affected by HIV/AIDS*. UNAIDS, Geneva. <http://www.unaids.org/publications/documents/persons/una9943e.pdf>

<sup>35</sup> See *Positive, Engaged, Involved: the participation of people living with HIV/AIDS in community-based organizations*. [http://www.popcouncil.org/horizons/ressum/plha\\_burkina.html](http://www.popcouncil.org/horizons/ressum/plha_burkina.html)

- First, in care activities. The demonstration of respectful and appropriate care for people living with HIV by respected religious leaders can be a formidable tool in challenging stigmatization at the community level by fostering respect and compassion for those living with HIV.
- Second, in prevention work. By engaging constructively with HIV-prevention efforts, religious leaders can reinforce, and add their authority to, messages encouraging risk-reduction and (where appropriate) behavioural change.

In the Sangha Metta project initiated in Thailand, for example, Buddhist monks are being trained to provide a range of prevention and care services to their local communities. Their multifaceted, but locally acceptable, activities are helping to seriously challenge stigma. Through the care they provide, monks provide their communities with role models of ‘compassion in practice’. Their willingness to have close and sustained contact with people living with HIV, and their efforts to help integrate people living with HIV into communal religious events, reinforce the message that affected individuals and their families are to be respected and supported.

In addition to helping to reduce discrimination, this visibly compassionate response also lessens something of the secrecy surrounding AIDS. This encourages disclosure, as people learn to trust that they will receive an appropriate response to acknowledging an HIV-positive status.

Religious leaders are also able to appropriate religious texts and cultural symbols in their struggle against stigma with powerful effect. These programmes show that AIDS is a shared concern, and to encourage a positive community response to people living with HIV. The Sangha Metta monks in Thailand have innovatively sponsored an HIV-themed parade float featuring floats of people living with HIV as part of the Loy Krathong parade, a traditional Thai festival. This transformed a cultural symbol into a high-profile statement of tolerance, in the process showing HIV to be a shared concern, rather than a ‘special’ issue to be separated off from everyday life. Reports of this event indicated that the inclusion of people living with HIV was accepted by the community. There have even been reported cases of HIV-positive people disclosing their status and joining the parade during the event<sup>36</sup>.

#### **4. Addressing stigma through participatory training**

Participatory educational approaches are essential in order to empower communities in a way that builds upon their existing knowledge and experience. Too often, in the past, stigma-reduction has been likened to a model of enlightenment, in which intervention specialists and those who ‘know best’ intervene to correct the negative attitudes and actions of others.

Participatory training at the community level can encourage people to challenge the accumulated and often unquestioned beliefs that reinforce stigma. These include the belief that people living with HIV have done something wrong, the belief that they deserve to be shunned and treated differently, and the belief that HIV is transmitted easily through everyday social contact.

The aim here must be not just to inspire individual behavioural change, but to create positive shifts in collective practice and thinking. Research suggests that people do not always know they are behaving in a stigmatizing way<sup>37</sup>. This emphasizes the importance of participatory awareness-raising to bring the unintended effects of people’s practices to their attention and challenge the use of language and local idioms that perpetuate stigma.

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<sup>36</sup> Posting at a list serve address at: Sea-aids@lists.inet.co.th 12/11/98

<sup>37</sup> International Centre for Research on Women (2002) *Understanding HIV-related stigma and resulting discrimination in sub-Saharan Africa: emerging themes from early data collection in Ethiopia, Tanzania and Zambia*. Research Update. See <http://www.icrw.org>.

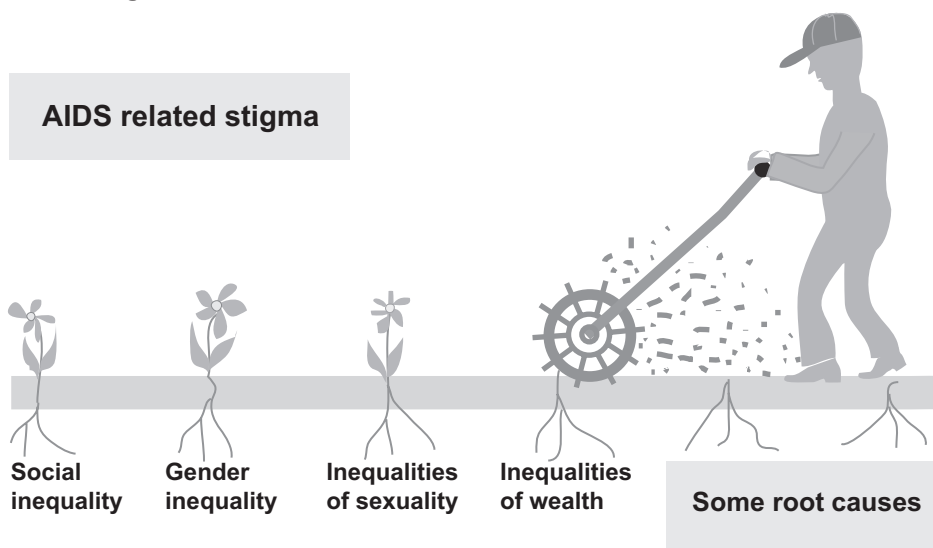
The coexistence of seemingly contradictory AIDS-related knowledge, of stigmatizing and sympathetic attitudes, and of discriminatory and caring practices offers a space within which to begin discussion. If implemented in a non-threatening way, participatory education can promote dialogue to develop communities' understanding of the epidemic and address the root causes of anxiety—fears relating to contagion and serious illness, ambivalence about sexual difference, and so on. Peer educators can play an important role in this kind of work.

## 5. Alliance-building and multisectoral action

Individuals experience stigma in many different settings. Multisectoral programmes, which target multiple contexts of stigma and discrimination and create alliances across different sectors of civil society, may therefore promote the scope and sustainability of response.

Stigma and discrimination need to be tackled not only in relation to AIDS, but also with respect to the other forms of inequality and exclusion that disempower those most vulnerable to infection. AIDS-related stigma plays into, and reinforces, these existing inequalities. Broad-based alliances are needed between those individuals and organizations active in preventing HIV transmission and in promoting care of those infected, and those working in other fields such as gender equality, sexual and reproductive rights, sustainable development and racial equality.

**Figure 5: Dealing with surface appearance is not enough. The root causes of AIDS-related stigma also need to be tackled<sup>38</sup>**



For example, greater attention needs to be paid to the gendered nature of HIV-related stigma. There is a need to address not only women's risks of infection, but their heightened vulnerability to stigmatization and discriminatory actions. AIDS-related stigma and discrimination against women are related to broader inequalities, including double standards that impact on health and well-being, women's unequal access to rights of property and access to children. The Ndola Diocese project in Zambia is but one example of a project that works in an integrated manner to tackle these broader vulnerabilities, working with (among other agencies) the Victim Support Unit of the Zambian police.

<sup>38</sup> This diagram was developed by Miriam Maluwa and Peter Aggleton.

The intersection of AIDS-related stigma with broader questions of identity and practice underline the importance of integrating AIDS programming into broader-based action. Programmes need to 'mainstream' AIDS. The Centre for the Study of AIDS at the University of Pretoria in South Africa, for example, is promoting discussion around AIDS-related stigma within a participatory education programme for students that situates AIDS within broad and critical debates of race and racism, culture, class and gender. This, together with discussion of citizenship, accountability and governance, allows for new understanding and is creating a new commitment to behavioural change. By integrating AIDS-related concerns into mainstream elements of the higher education curriculum, including subjects such as law, agriculture and engineering, greater understanding of the issues may emerge, de-stigmatizing discussion of AIDS, and emphasizing that HIV is everyone's concern.

## **6. Raising awareness through the media**

Media, especially via radio and television drama can be used with powerful effect to promote positive attitudes towards people living with HIV. The Soul City initiative in South Africa, for example, which has a target audience of millions, has consistently included in its drama series themes relating to AIDS-related stigma and discrimination, the difficulties of disclosure in a non-supportive environment, and the necessity of treating people living with HIV with compassion and respect. The indications are that Soul City's work is contributing to greater openness in talking about matters relating to sexuality, increasing awareness that people living with HIV can live healthy, productive lives, and that it is having a 'knock-on' effect in enabling community leaders, teachers and health service providers to use the messages in other arenas. All over the world, there have been similar initiatives using both television and radio to raise awareness and to offer people positive role models in the face of the epidemic.

## **7. Creating a supportive and confidential space for the discussion of sensitive topics**

In settings where public discussion of matters relating to AIDS and sexuality is sensitive or 'taboo', the chance for people to access information and discuss their concerns in a safe and confidential space can encourage greater openness and sensitivity. In settings where pervasive stigma and fear attached to AIDS discourage frank discussion of matters relating to HIV and prevention, increased openness is a prerequisite for tackling stigma. Telephone hotlines, counselling centres, support groups and drop-in centres have offered hundreds of thousands of people the chance to talk more openly about their experiences, fears and anxieties.

## **8. Counselling and support to families, including affected children**

The provision of counselling and support to families of people living with HIV is an important component of care programmes, since it can do much to reduce stigma and discrimination. It can do this not only by reducing families' fear and stigmatization towards affected individuals, but also by facilitating greater openness and promoting dialogue about the family's circumstances within and beyond the household. Secrecy about serostatus can limit the ability of people living with HIV to plan for their children's future. Succession planning is one example of an approach that seeks to reduce the likelihood of discrimination and marginalization being suffered by surviving family members, including children. It seeks to encourage people living with HIV and their families to plan constructively for the death of a relative, so that children are prepared for it. Succession planning not only aims to increase dialogue about AIDS within

families, but to develop practical ways for children to get support from other parts of their kin networks and community.

## **9. Adopting rights-based anti-discriminatory policies and legislation**

Institutional settings, including workplaces and health-care centres, provide an excellent opportunity to set standards to protect human rights and establish a supportive environment for those living with HIV. Rights-based AIDS policies offer powerful instruments with which to combat discrimination in institutional settings. 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<sup>39</sup>. Beyond this, national formations of employer groups such as the Thailand Business Coalition against AIDS can help to standardize workplace approaches to antidiscrimination and enhance the capacity of businesses to respond to the epidemic within a human rights framework.

Within health-care services, codes of ethics and professional conduct need to be in place and enforced, and their application to AIDS taught within professional training curricula. In addition, internal processes within specific health services are required to enable managers and health workers to formulate plans of action that help ensure a sense of ownership and shared pride in changing negative attitudes towards people living with HIV, and improving their quality of care. One example of this kind of initiative is the ‘patient-friendly’ project being implemented in some Indian hospitals.

Across a range of health-care settings, straightforward practical measures such as standardized and universally applied guidelines relating to infection control are required to reduce any stigma-enabling anxieties that health-care workers may have about HIV transmission. The consistent use of universal precautions will also help to protect the identities and rights of infected patients.

## **10. Challenging discrimination and providing redress for violations of laws and human rights**

Antidiscrimination laws, policies, and codes of professional ethics will remain ineffective in the absence of mechanisms for redress in circumstances where violations occur.

Legal aid institutions and lawyers’ collectives specializing in AIDS, such as the Lawyers’ Collective in India and the Legal Assistance Centre in Namibia, have a critical role to play in ensuring the monitoring and enforcement of human rights, and in tackling instances of discrimination and human rights violations. Training and support may be needed to develop such organizations and their approaches to human rights and AIDS.

Support is also needed to establish and extend community-based legal services to tackle instances of discrimination and violations of human rights. Basing such organizations in existing AIDS service organizations, or within associations of people living with HIV, may be one way of helping develop trust among those who have experienced discrimination, especially where such organizations are already valued and respected by their communities. Training schemes to develop the capacity of such organizations to provide in-house para-legal counselling and advice is likely to increase the access of people living with HIV to legal protection.

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<sup>39</sup> <http://www.ilo.org/public/english/protection/trav/aids/code/codemain.htm>

## **11. Promoting access to HIV and AIDS treatments**

Although many countries are signatories to international conventions on human rights that specify the right to all people to the highest attainable standard of health care, millions of people living with HIV are denied access to basic and effective treatments for HIV. Access to treatment, both to medicines to treat opportunistic diseases and antiretroviral therapy, may help reduce stigma by enabling people living with HIV to live positively and productively for longer. Such intervention is likely to increase their quality of life significantly, as well as reducing others' fear of AIDS by helping people to understand that it is possible to manage and live with the disease. Examples of programmes where such results have been indicated are the workplace care programme at VW in Brazil and the HIV Equity Initiative in Haiti.

The availability of free and comprehensive public health care and effective treatments, whether in community settings or through workplaces, may also encourage more people to come forward for confidential voluntary counselling and testing and follow-up care. This has been witnessed in the HIV Equity Initiative in Haiti, where the provision of free antiretroviral therapy for antenatal attenders and the general population has brought about a dramatic increase in the number of people seeking testing. This, in turn, has provided increased opportunity for counselling and prevention work.

## Conclusions

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- Tackling HIV-related stigma, discrimination and human rights violations is critical in slowing the impact of the epidemic. Stigma and discrimination impact negatively on every aspect of the prevention-care-treatment continuum, as well as greatly increasing the suffering associated with living with HIV.
- Stigma, discrimination and human rights violations are intimately linked, reinforcing and legitimizing each other. Multifaceted action, sustained over time, is needed to prevent stigma, challenge discrimination when it occurs in specific settings, and promote and protect HIV-related human rights.
- The case studies detailed here demonstrate some success in tackling stigma, discrimination, and the abuse of human rights. They also reveal evidence of real innovation adapted to local circumstances and needs. Ongoing evaluation and documentation remain important.
- While reducing stigma is often not the sole or even the primary focus of some programmes, numerous HIV prevention and care activities produce positive effects on stigma and discrimination as by-products of their main objectives. Nevertheless, anti-stigma and antidiscrimination elements could be integrated more consistently and explicitly into AIDS programming practice than is currently the case.
- There exist many entry points for programming to tackle stigma, discrimination and human rights violations. Many of the programmes profiled here employ multiple strategies to tackle stigma, discrimination and human rights violations.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) brings together ten UN agencies in a common effort to fight the epidemic: the Office of the United Nations High Commissioner for Refugees (UNHCR), the United Nations Children's Fund (UNICEF), the World Food Programme (WFP), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations Office on Drugs and Crime (UNODC), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank.

UNAIDS, as a cosponsored programme, unites the responses to the epidemic of its ten cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV/AIDS on all fronts. UNAIDS works with a broad range of partners – governmental and nongovernmental, business, scientific and lay – to share knowledge, skills and best practices across boundaries.

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## The UNAIDS Best Practice Collection

- is a series of information materials from UNAIDS that promote learning, share experience and empower people and partners (people living with HIV/AIDS, affected communities, civil society, governments, the private sector and international organizations) engaged in an expanded response to the HIV/AIDS epidemic and its impact;
- provides a voice to those working to combat the epidemic and mitigate its effects;
- provides information about what has worked in specific settings, for the benefit of others facing similar challenges;
- fills a gap in key policy and programmatic areas by providing technical and strategic guidance as well as state-of-the-art knowledge on prevention, care and impact-alleviation in multiple settings;
- aims at stimulating new initiatives in the interest of scaling up the country-level response to the HIV/AIDS epidemic; and
- is a UNAIDS interagency effort in partnership with other organizations and parties.

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HIV-related stigma and discrimination and human rights violations constitute great barriers to preventing HIV infection; providing care, support and treatment; and alleviating the impact of the epidemic.

This publication documents case studies of successful action addressing HIV-related human rights violations, stigma and discrimination.

Although more effort is required, programmes in a range of countries are innovatively and successfully challenging HIV-related stigma, discrimination and human rights violations. Actions have been of three broad types:

- *Stigma reduction approaches*—frequently consisting of community-based HIV prevention and AIDS care programmes, mobilising a wide range of actors
- *Specific antidiscrimination measures*—often focused on institutional settings such as places of work or health services; and
- *Legal and human rights mechanisms*—using legal means to promote human rights as well as challenge and seek redress for discrimination against people living with HIV.

These programmes demonstrate that there are many potential entry points for the reduction of AIDS-related stigma and discrimination, and the promotion of the human rights of people living with HIV.



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