DFID Department for International Development

Taking Action Against HIV Stigma and Discrimination

GUIDANCE DOCUMENT AND SUPPORTING RESOURCES

On the Cover:

Micah Chansa
ZAMBIA Kabuta village, Nchelenge

Micah Chansa is HIV positive. When she told her father and mother they rejected her. Relatives refused to come inside her house. Her three children who were then aged 12, 10 and 6 looked after her when she fell ill. Now she is on ARVs and works as a cook and farms cassava.

Her family has accepted her now, and her sister is doing her hair again.

Cover Photo by Pep Bonet / Panos Pictures

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November 2007

Acknowledgments

This document was researched and written by Dara Carr (Independent Consultant) and Laura Nyblade of the International Center for Research on Women (ICRW, www.icrw.org). Critical editorial guidance and input was provided by Dieneke ter Huurne and Clare Shakya of DFID. The authors are also grateful to John Leigh, Malcolm McNeil, Michael O'Dwyer, Jianrong Qiao and Martin Taylor of DFID for their input. Report designed by Serendipity Creative (www.serendipitycreative.com).

This document benefited from the contributions of a number of individuals at ICRW. Special thanks are due to Traci Eckhaus and Annie Conner for their ongoing research support. The authors also wish to thank Anne Stangl, Ellen Weiss and Jessica Ogden for technical input and Sandra Bunch and Sandra Won for publication management.

Finally, the authors wish to express their gratitude to DFID for supporting this work and for DFID's ongoing commitment to improving the health and quality of life of people affected by HIV.

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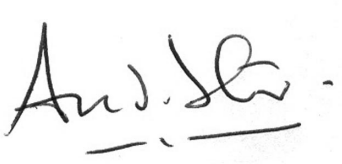
Foreword

Taking action against HIV related stigma and discrimination is essential for achieving Millennium Development Goal 6 "To halt and begin to reverse the spread of HIV and AIDS".

Acts of discrimination deny people's rights to information, to services to protect them against HIV infection, and to receive appropriate treatment, care and support when HIV-positive. Fear of stigmatisation and discrimination discourages people from seeking information on HIV and AIDS, coming forward for counselling and testing, disclosing their status or accessing AIDS services. We will not achieve Universal Access without reducing stigma and discrimination.

There is an urgent need to accelerate efforts and we have the tools to do so. DFID has supported a range of interventions aimed at tackling HIV stigma and discrimination. Our work and that of others has contributed to a better understanding of stigma and discrimination and how to reduce it.

In this document we have sought to describe best practice and distil the key lessons. It provides a useful tool for DFID staff and others working on HIV and AIDS to incorporate a strong focus on tackling stigma and discrimination in their work.



Andrew Steer
Director Policy and Research Division
Department of International Development

Guidance Document

"Neighbours will tell me there is a sick person in the back bedroom but, when I arrive, the family denies it. The families themselves prevent anyone from helping them."

—Community Health Worker providing AIDS care in KwaZulu-Natal province, South Africa[1]

The Challenge of HIV Stigma and Discrimination

Worldwide, people living or associated with HIV and AIDS are subject to stigma and discrimination. They may lose their employment and livelihoods, property, social status, children and friends. They may be given substandard care or even refused care at health facilities.

HIV stigma and discrimination are violations of human rights and undermine public health efforts to tackle HIV and AIDS. Stigma refers to the beliefs and attitudes that deeply discredit a person or group because of an association with HIV. This leads to discrimination—actions or omissions that harm or deny services or entitlements to stigmatised individuals.

Stigma and discrimination are particularly harsh for populations that are already socially excluded or have unequal status in society. These groups often experience stigma and discrimination based on several markers (e.g. related to gender, sexuality, drug use, ethnicity, etc)—also called multi-layered stigma. Women and children, for example, are more prone than men to property grabbing, abandonment and violence as a result of their HIV status or association with the disease. Men who have sex with men, injecting drug users, sex workers and prisoners often face greater discrimination when diagnosed with HIV. At the same time, these are the people with the fewest resources to cope with the consequences.

The consequences of stigma and discrimination, and often just the fear of these consequences, keep people from seeking HIV information, adopting preventive behaviour, getting tested, disclosing their serostatus, and accessing treatment. In some cases, stigma prevents families from giving or accepting care. People living with HIV may not always take their drugs at the correct time or in the correct way, in order to conceal their positive status. As a result, stigma and discrimination compromise AIDS responses and drive the spread of HIV.

In 2006, UNAIDS categorised HIV stigma and discrimination—along with inequity and human rights abuses—as primary obstacles to scaling up services in HIV and AIDS and achieving Universal Access to comprehensive HIV prevention, treatment care and support by 2010[2]. Even where services are available, uptake is often lower than desired due to stigma and discrimination. In order to achieve Universal Access, countries should aim to increase the delivery of AIDS services as well as implement extensive, concerted efforts to reduce stigma and discrimination.

Despite the importance of these issues, stigma and discrimination are neglected in most national and international AIDS responses. Peter Piot, UNAIDS Executive Director, has observed, "Since the beginning of the epidemic, stigma, discrimination and gender inequality have been identified as major causes of personal suffering, and as major obstacles to effective responses to HIV. Yet there has never been serious political and programmatic commitment to doing anything about them. All these efforts have been relegated to the bottom of AIDS programmes, together with human rights, and often with no funding attached to them."[3].

Recent research and programme developments have set the stage for effective, scaled-up interventions that can generate broad reductions in stigma and discrimination. By building on this work and the latest knowledge and practices, DFID can continue to advance efforts. This paper highlights current best practice responses to stigma and discrimination and provides guidance on how DFID can help build further evidence and accelerate action for change. Though this guidance has been developed specifically for DFID staff, it will be of interest and benefit for others working on HIV and AIDS and can be shared with interested partners.

DFID's Response to the Challenge

Taking Action, the U.K.'s strategy for tackling HIV and AIDS in the developing world, recognises the importance of a rights-based response to the epidemic.

> "We will ensure that respect for human rights is at the centre of our strategy. Lack of respect for human rights intensifies vulnerability to HIV and hampers effective health for people with HIV and AIDS. We will take action to confront stigma and discrimination, and give particular attention to supporting women, young people, including orphans, and other vulnerable groups. These people are most affected by HIV and AIDS but they are often neglected by governments and donors alike."
>
> —DFID[4]

DFID has supported a wide range of efforts against stigma and discrimination throughout the world. These efforts span three major approaches:

(1) Prevent and reduce stigma.

(2) Challenge discrimination, particularly in institutional settings.

(3) Promote, protect and fulfil human rights.

Most of DFID's activities fall under the first approach and focus on reducing stigma associated with HIV and/or high-risk behaviours. Specific activities include raising awareness with public education, empowering excluded groups to advocate for their rights and improved services, and mobilising leaders and role models to foster openness and respect[5].

DFID has the experience, resources and access to drivers of change, particularly leaders and decision makers, to continue making a difference. Some possibilities for further action are outlined below.

Promote awareness and action within DFID

Effective action against stigma and discrimination requires a strong understanding of the issues within organisations. Organisations should 'lead by example' and actively address stigmatising attitudes and practices that may exist within the organisation.

HIV stigma and discrimination occur within a wide range of settings—including in the workplace. Organisations that are committed to reducing stigma and discrimination should work to create a working environment in which people living with or affected by HIV and AIDS are free from discrimination or the fear there of. The Foreign and Commonwealth Office (FCO), DFID and British Council recognise their responsibilities as employers to challenge HIV stigma and discrimination in the workplace and have adopted an HIV and AIDS workplace policy. DFID staff can play a role in helping to create a positive enabling environment by taking an active stand against HIV stigma and discrimination.

In addition, it is important that staff have the knowledge and tools to effectively reduce HIV stigma and discrimination. A solid understanding of the issue and how it can be addressed is important for effective advocacy and directing support to the most promising programmes.

Possible actions include:

- Raise awareness of HIV stigma and discrimination, its adverse impact on the AIDS epidemic and country responses and the need to act among DFID staff by disseminating the overview of HIV stigma and discrimination provided in the *Supporting Resources* (section 1) and suggesting or organising sessions on the issue during staff retreats.
- Organise stigma and discrimination-reduction workshops as part of DFID's workplace policy on HIV and AIDS. The most effective workshops typically include people living with HIV (examples of possible workshops are included in section 5 of the *Supporting Resources*).
- Disseminate and promote the use of tools for effective advocacy and action, such as the evidence-based talking points and the case studies of successful interventions included in sections 2 and 3 of the *Supporting Resources.*
- Give greater prominence to the need to address HIV stigma and discrimination in DFID policies, programmes and country analysis. For example, ensure that the issue is recognised and addressed in DFID's *Country Assistance Plans* and accompanying analysis, including Social and Governance appraisals.

Promote Awareness and Action Among Other Stakeholders

Efforts to reduce HIV stigma and discrimination are often neglected in country responses, because of a lack of awareness and knowledge on the issue, the public health benefits of taking action and ways to address stigma and discrimination. Additionally, stigma may be perceived as too culturally specific, politically sensitive and complicated to address.

Recent studies provide evidence that stigma and discrimination are remarkable similar across different settings and that effective action is possible. Disseminating that knowledge is an important step towards creating increased leadership and high-level commitment to tackle the problem.

The FCO leads in developing and delivering the UK Government's international agenda on human rights and is an important partner for this agenda. Ambassadors could help raise awareness and provide leadership to reduce HIV stigma and discrimination through their interactions with world leaders. In 2006, the International Development Committee (IDC) recommended that DFID work closely with the FCO on the governance and human rights aspects of HIV and AIDS.

Possible actions include:

- Share information on HIV stigma and discrimination with staff at the FCO.
- Give greater prominence to the public health benefits of reducing HIV stigma and discrimination in policy dialogues with national governments and promote inclusion of effective strategies in national AIDS plans. (*Supporting Resources*, section 2)
- Demonstrate that change is possible. Practical and proven tools for reducing stigma and discrimination exist and examples of successful interventions are available. (*Supporting Resources*, sections 3 and 4)

- Advocate for and support meaningful participation of people living with HIV and other groups in national planning, policymaking and other processes related to the AIDS response.
- Promote government programming against stigma and discrimination. Engage a range of ministries, including health, justice, interior, defence and education, in discussions. Additionally, national human rights commissions, law reform commissions and parliamentary committees have important roles to play.

Build the Evidence Base

Research on stigma and discrimination has made great progress towards building a strong evidence-based on the issue in recent years, but knowledge gaps remain.

Though a lot of qualitative data is available, quantitative data on stigma and discrimination remains scarce, particularly related to uptake of HIV prevention, care and treatment services. This is partly because validated indicators that can document and measure stigma and discrimination were unavailable until recently. However, several tools and indexes are now available to help overcome this lack of data (see the section 'Measure results' below and Supporting Resources, section 6). This also provides the opportunity to evaluate interventions for their impact on stigma and discrimination and strengthen our understanding of effective approaches.

Other areas warranting greater investigation include: the relationship between HIV stigma and discrimination and factors such as stage of epidemic and availability of treatment; the experiences of stigma and discrimination among vulnerable populations; and effective interventions for addressing multi-layered stigma.

Possible actions include:

- Identify and support research programmes that help fill existing knowledge gaps, including supporting documentation of the experiences of people living with HIV and AIDS through the PLHIV Stigma Index, which can provide better data on stigma and discrimination and record trends over time (*Supporting Resources*, section 6).
- Build the capacity of organisations of people living with HIV to help shape and implement research.
- Assess emerging best practices for scale up and incorporation into government and other programmes.
- Share lessons learned across DFID departments and country offices and with interested parties.
- Require monitoring and evaluation of stigma and discrimination reduction efforts, as an integral part of AIDS programmes.
- Support efforts that incorporate ongoing assessment to increase understanding of effective interventions and how efforts can be taken to scale.
- Ensure DFID-supported projects and programmes are evaluated using reliable and valid indicators and tools. Indicators exist for evaluating programmes working with a range of target groups. (*Supporting Resources*, section 6)

Accelerate Efforts Through Programming

Through its partnerships and programming, DFID is well positioned to advance stigma and discrimination mitigation efforts and ensure a comprehensive response. Numerous entry points exist.

In 2006, an audit of DFID's work of addressing HIV stigma and discrimination revealed that DFID supports around 100 programmes and projects. However, these make up a relatively small part of DFID's AIDS response and there is room to integrate and scale up interventions. It is important that the interventions supported comply with the general principles for tackling stigma and discrimination and measure results.

Possible actions include:

- Review programme proposals on their potential impact on stigma and discrimination. (See Box 2 for questions in reviewing programme proposals and memoranda)
- Encourage DFID supported organisations to sign up to the *Code of Good Practice for NGOs Responding to HIV and AIDS*[8] and specifically address stigma and discrimination. The DFID-supported *Code of Good Practice* provides a set of principles and practices for an effective, rights-based response to HIV.
- Support activities that challenge discrimination in institutional settings and protect and promote human rights. For example, anti-discrimination efforts in public sector health care would improve key health outcomes.
- Promote anti-stigma and discrimination efforts in areas beyond health, such as education and justice, which use the emerging best practice identified below.
- Where possible, ensure a comprehensive response across programmes (e.g. complement the empowerment of people living with HIV and AIDS with mass media interventions and legal reform to protect their rights).

BOX 1: INTEGRATING ANTI-STIGMA AND DISCRIMINATION EFFORTS INTO EXISTING AND NEW DFID PROGRAMMES

The following questions can be asked to help integrate a focus on reducing stigma and discrimination.

- Are investments likely to be less effective because of stigma and discrimination?
- If so, does the programme or proposal recognise this and understand the need to reduce stigma and discrimination?
- What is already being done or being proposed to address stigma and discrimination?
- Is the suggested action appropriate and adequate? Does it include an active role for people living with HIV? Address multiple target groups? Operate on different levels? Challenge underlying drivers and multiple sources of stigma? Is it sufficiently intensive to affect change?
- If nothing is being done, would the programme benefit from a stigma and discrimination reduction component?

Intervention Lessons

General Principles

In recent years, researchers and practitioners have made significant progress in conceptualising, modelling and defining different dimensions of stigma and discrimination[7,9–16]. Practitioners have developed practical tools to reduce HIV stigma and discrimination[18] and implemented successful interventions with a range of target groups[19–21].

Research in settings as varied as Ethiopia, India, Tanzania, Vietnam and Zambia found stigma and discrimination to be remarkably consistent across contexts in its causes, forms and impact[6]. Given these commonalities, it is suggested that a common core response to stigma and discrimination is justified, with minor modifications by context. These experiences have led to the development of general principles for tackling stigma and discrimination, which include addressing the causes of stigma and breaking the cycle of stigmatisation and discrimination. The principles apply to any target group and are most effectively implemented through participatory methodologies.

ADDRESS THE CAUSES OF STIGMA

The overarching principle for tackling stigma is to address its immediate and underlying causes.

Three causes of stigma are:

- Lack of awareness and knowledge;
- Misconceptions around HIV transmission that lead to fear of acquiring HIV through everyday contact with infected people; and
- Values linking people with HIV to behaviour considered improper and immoral.

For change to occur, people must be aware of their stigmatising attitudes or discriminatory actions and understand the damaging impact this has. This is not always the case. Fear of acquiring HIV through everyday contact leads people to take unnecessary, and often stigmatising, actions such as physically isolating persons (suspected to be) living with HIV. Value-driven stigma links people with HIV to behaviour considered improper and immoral, resulting in shame, blame and judgment. The judging and blaming attitudes, which typically rationalise discriminatory acts, are entrenched in social, gender and sexual norms.

The underlying drivers of HIV stigma may be addressed by:

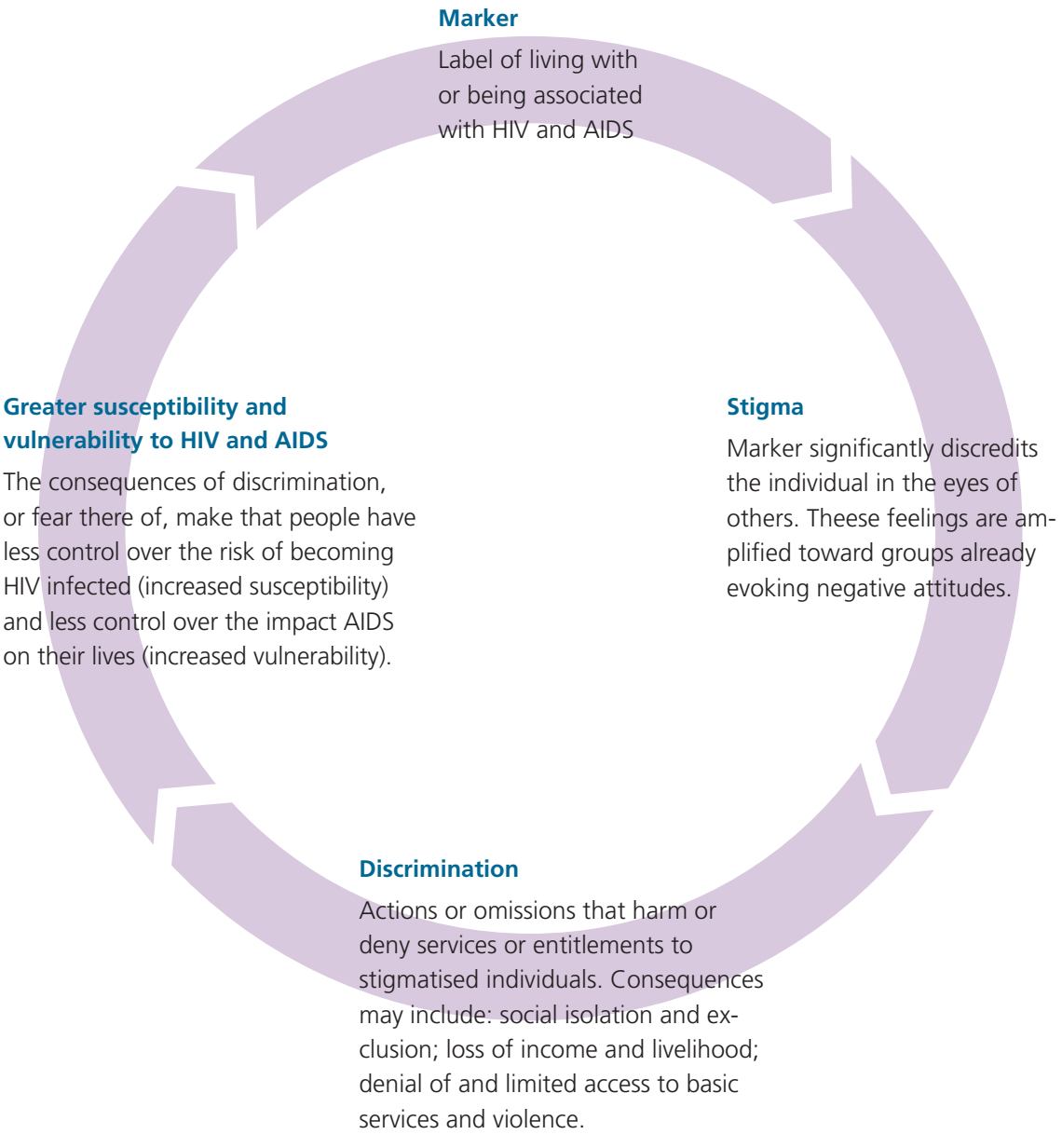
- Creating an awareness of what stigma is and the (public health) benefits of reducing it;
- Fostering motivation for change;
- Addressing fears and misconceptions about HIV transmission;
- Discussing "taboo," topics including gender, violence, sexuality and injecting drug use; and
- Providing the skills to challenge stigma and change behaviour[7, 22].

BREAK THE CYCLE OF STIGMATISATION AND DISCRIMINATION

The process of stigmatisation and discrimination is similar in different settings[23]. Stigma and discrimination tend to be mutually reinforcing, in a dynamic cycle (see Figure 1). Stigmatisation leads to discrimination, which leads to disadvantages that compromise an individual and, in turn, foster greater vulnerability and social exclusion.

The cycle suggests a number of entry points for reducing stigma and discrimination. Ensuring greater confidentiality could mitigate the "marker" of stigma, facilitating concealment and preventing stigma. Taken on its own, however, this approach does not address the underlying drivers of stigma. Participatory education and social marketing might reduce "stigma" or the association of HIV and AIDS with negative traits. Actions to reduce discrimination could minimise disadvantage, while measures to reduce susceptibility and vulnerability could halt or slow the reinforcing cycle of stigma and discrimination.

FIGURE 1: CYCLE OF STIGMATISATION AND DISCRIMINATION



Adapted from Sartorius, N., 2006.

Emerging Best Practice

Although evaluation data are limited, there are multiple examples of promising approaches and effective interventions that demonstrate results[1, 5, 6, 28–33] (*Supporting Resources*, section 3).

Comprehensive approach

There are a number of lessons from stigma and discrimination-reduction initiatives to date. The first is that a country-level response to stigma and discrimination should address the causes of stigma through a range of approaches and operate at multiple levels with multiple target groups (see Table 1). Stigma and underlying norms around gender, sexuality and other factors are often enforced at the family, community, institutional, and legal and policy levels. Thus, a comprehensive response to stigma and discrimination, aimed at creating an enabling environment for individuals to practice prevention and access services, will have the greatest and broadest impact.

TABLE 1: EMERGING BEST PRACTICE TO REDUCE STIGMA AND DISCRIMINATION

An effective national response…	
Addresses underlying causes	Interventions need to address the root causes of stigma and help break the cycle of stigmatisation and discrimination.
Addresses multiple layers of stigma	Vulnerable groups typically experience stigma from multiple sources (e.g., drug use, sexuality, gender, sex work, HIV). Thus, interventions that address only HIV stigma may not improve prospects for these groups or facilitate the response to AIDS.
Operates at multiple levels	Individual; family; community; organisational/ institutional; and government/ legal.
Engages multiple target groups, potential change agents, marginalised and vulnerable populations	These groups might include: opinion leaders (e.g., politicians, faith-based leaders), frontline HIV responders (e.g., health care workers, NGO and community workers), people living with HIV and other stigmatised groups, communities, the media, private sector, schools, police, and the judiciary.
Employs a range of approaches: 1. Prevent and reduce stigma 2. Challenge discrimination, particularly in institutional settings 3. Promote and protect human rights	Successful approaches will involve a combination of: ■ Strengthening and building capacity of stigmatised individuals and groups (e.g., skills building, network building, counselling, training, income generation); ■ Contact or interaction with people living with HIV and other stigmatised people (e.g., men who have sex with men and sex workers); ■ Participatory and interactive education; ■ Behaviour change communication (e.g., media campaigns, edutainment programmes); ■ Institutional reform (e.g., addressing discrimination in workplaces, health care settings, schools and other institutions); ■ Policy dialogue, legal and policy reform with enforcement and mechanisms for redress, especially at local levels; and ■ Provision of services, care and treatment.

The range of responses to date varies considerably. Some efforts represent more comprehensive approaches, while others are more narrowly focused—e.g. aimed at eliminating discrimination within health care institutions. Research suggests interventions combining a range of approaches are more effective. For instance, educational strategies to improve knowledge of HIV and AIDS are common, but, when used alone, have limited effectiveness on attitudes[24-27]. Such strategies are more effective when combined with efforts that challenge social norms and promote a legal environment supportive of the rights of people living with HIV and AIDS. Efforts that combined pilot projects and policy advocacy have also had promising results. That said, comprehensive interventions are not always possible or practical, and some narrowly focused interventions can be effective. For the greatest impact, more narrowly focused interventions should be part of a comprehensive, national response to stigma and discrimination.

Participatory Approach

A participatory approach is at the core of several promising stigma-reduction interventions[18]. Participatory education—which encourages people to reflect on their own attitudes and actions—is especially effective for catalysing individual change around stigma and discrimination at any level, particularly the community level[7, 35]. This model uses interactive workshops with reflection exercises, role-plays and discussions (*Supporting Resources*, section 5). The approach fosters greater understanding of the harm stigma causes and the need to change attitudes and behaviours. Involving people living with HIV as facilitators adds to the transformative power of these workshops. Action planning is an important end result.

Interventions applying a participatory approach are being implemented in diverse settings, with a variety of key audiences, including communist party officials in Vietnam; teachers in Zambia; and health care workers in India, Vietnam and Tanzania[20,21, 37-39]. In Vietnam, a workshop led leaders of the Commission for Ideology and Culture of the Communist Party, which controls all media and party messaging, to formulate a set of media guidelines on conducting non-stigmatising reporting on HIV and AIDS[40]. (See *Supporting Resources*, sections 3 and 4).

In a recent global review of stigma-reduction interventions, researchers concluded that the most promising efforts include a combination of participatory education, empowerment of people living with HIV, and indirect or direct interaction between people living with HIV and key audiences[34]. These efforts could be scaled up and effectively promoted by organisations. Where programmes include one of the identified components, but not the others, efforts should be made to integrate them.

Empowerment approach

The active involvement of people with HIV and AIDS is crucial for developing and implementing effective anti-stigma and discrimination efforts[33,36]. Where persons affected by stigma and discrimination have been empowered to become agents of change and act collectively to challenge discrimination, important successes have been made.

When pursuing an empowerment approach, intervening first to address internalised stigma and fostering community support may be necessary before people can publicly disclose their serostatus and demand their rights. Speaking out to challenge discrimination also can be difficult. People living with HIV may need new skills and ongoing support to take active, visible roles in anti-stigma and discrimination efforts.

Internalised stigma—feelings of depression, isolation, worthlessness, shame and guilt that may accompany a diagnosis of HIV—can be a major obstacle to empowering people living with HIV. Reducing internalised stigma through peer-to-peer support groups like post-HIV clubs can lay the foundation for coping with one's status, adopting positive living, accessing services and participating in anti-stigma efforts. While important, these activities do not diminish the need to foster an enabling environment for change at the community level. Intervening in communities is key to facilitating critical thinking about the factors undermining HIV prevention and the humane treatment of people with AIDS[41].

Groups and networks of people with HIV can play an important role in advocating for community-level change and acting collectively to challenge discrimination. Many such organisations, however, lack the capacity to be meaningfully involved in responses to the epidemic. DFID supports capacity building of several national and global networks of HIV groups and many DFID country offices have suggested that future anti-stigma and discrimination efforts should support greater involvement of people living with HIV in programmes, policies and funding decisions[5].

Promoting enabling environments

The power of anti-stigma and discrimination interventions is often magnified through policies and laws supportive of the needs and rights of those most affected by the epidemic, and through availability of treatment and services. For example, empowerment efforts by South Africa's Treatment Action Campaign, encouraged members to announce they are "HIV positive" and assert their rights to treatment. This was greatly facilitated through a supportive legal framework[28]. UNAIDS and other international bodies highlight the Treatment Action Campaign as a successful model. A key element of this approach is the participation of people living with HIV in advocacy and other efforts.

Operating at the policy and legal levels, a number of interventions have successfully convinced governments to better address the needs of vulnerable groups and to make services and treatment more widely available. DFID-supported activities in China helped transform the attitudes of government officials toward vulnerable groups and have led to scaled-up prevention and treatment efforts (*Supporting Resources*, section 3).

Groups of people living with HIV have successfully advanced legal protections, particularly those groups aligned with legal organisations. Legal groups, such as the Lawyers' Collective in India, have successfully defended the rights of people living with HIV. In general, policy advocacy and programmes promoting human rights can play an important part in a broad-based stigma and discrimination-reduction strategy, fostering an enabling environment for social change[33, 36].

Measure Results

Reliable and valid methods exist for evaluating stigma-reduction programmes[17]. These include indicators that identify the underlying drivers of stigma and demonstrate the extent of discrimination.

Monitoring and evaluation should be an integral part of any intervention, whether programmes focus solely on stigma reduction or incorporate stigma and discrimination reduction into ongoing activities. The nascency of stigma-reduction programming calls for careful evaluation to identify effective models for replication and scaling-up[92]. The following key questions can be used to assess proposed or ongoing programmes:

- Does the programme include monitoring and evaluation of stigma and discrimination reduction?
- Are the proposed indicators appropriate for measuring what the programme seeks to accomplish?
- Does the proposed evaluation recognise that different dimensions of stigma need to be measured separately?
- Is the time frame realistic? Do the proposed indicators reflect what can be accomplished during the life of the programme?
- Are the indicators targeting the appropriate population?
- Are the proposed outcomes measurable?
- Do proposed outcomes reflect the organisation's capacity to measure results?

BOX 2: WHY MEASURE RESULTS?

Determine Effectiveness:

Ongoing monitoring and evaluation with reliable, quantitative measures will determine if the intervention is effective; what aspects of stigma and discrimination are most responsive to the intervention; and any needed modifications.

Identify Effective Models for Scale Up:

Solid evaluations will help identify which approaches are most likely to be broadly successful and how they should be applied.

Detect Any Unintended Consequences:

Measurement can show if the programme is inadvertently exacerbating stigma and discrimination and what aspects may need to be changed.

Conclusion

Stigma and discrimination reduction is key to more effective HIV prevention, treatment, care and support.

Although responses to reduce stigma and discrimination have been neglected in many country programmes, both the knowledge and tools exist to address it successfully and mitigate its effects. DFID has supported a wide range of efforts against stigma and discrimination throughout the world. By building on this work, using the latest knowledge and practices, DFID can continue to help programmes advance. Possible actions that DFID staff can take to help accelerate global leadership and action on HIV stigma and discrimination include:

- Promoting awareness and action both within DFID and among other stakeholders—e.g. by disseminating information and evidence on HIV stigma and discrimination and the impact on the epidemic and give greater prominence to the need for action in consultations, policies and plans;

- Building the evidence base—e.g. by supporting research programmes that help fill existing knowledge gaps and develop emerging best practices for scale up; and
- Accelerating efforts through programming—e.g. by reviewing programme proposals specifically on their potential impact on stigma, promoting anti-stigma and discrimination efforts in areas beyond health, such as education and justice.

It is important that the interventions supported comply with the general principles for tackling stigma and discrimination, using appropriate approaches and accurately measuring results. Interventions aiming to reduce HIV stigma and discrimination should address the causes of stigma and attempt to break the cycle of stigmatisation and discrimination. Interventions that have successfully done so include those that have taken a comprehensive, participatory or empowerment approach, that work towards creating enabling environments or a combination of several approaches.

The DFID AIDS and Reproductive Health team can be contacted for further support and advice.

Supporting Resources

"We are really living under the fear of discrimination…It has silenced us…Because of this we cannot take care of ourselves and others".

—Ethiopian woman living with HIV[43]

SECTION ONE: UNDERSTANDING HIV STIGMA AND DISCRIMINATION AND THE IMPACT ON AIDS RESPONSE

HIV stigma refers to the beliefs and attitudes that deeply discredit a person or group because of an association with HIV. This leads to discrimination—actions or omissions that harm or deny services or entitlements to stigmatised individuals.

People living with and affected by HIV are subject to loss of employment, livelihoods and property, school expulsion, violence, social exclusion, denial of medical services, and lack of care and support. The social and economic consequences resulting from HIV stigma and discrimination can be as devastating as the illness itself. These consequences, or often just the fear of them, contribute to the spread of HIV. People who live in fear and denial of HIV are less likely to adopt preventive behaviour, test for HIV, disclose their serostatus to others, and access care and treatment.

Understanding HIV Stigma and Discrimination

Stigma and discrimination are globally prevalent, pervasive and damaging. Researchers have found evidence of stigma and discrimination in contexts as diverse as China, Mexico, South Africa and the United States[25, 44-47]. It exists in high HIV prevalence countries such as Botswana and in lower prevalence settings such as India[49, 50]. Stigma and discrimination are not rare or isolated events and operate at multiple levels: within families; communities; institutions, such as health care facilities and places of employment; in the media; and in government policies, laws and legislation[6, 7] (See Table 1).

Forms of stigma and discrimination

Stigma and discrimination take on multiple forms, which fall into four broad categories: physical, social, verbal and institutional. Physical stigma and discrimination includes physical isolation and violence. Expressions of physical stigma and discrimination range from separate sleeping quarters in the home to the refusal to be in physical proximity on buses or in places of worship. Social stigma and discrimination includes social isolation, loss of identity and role, and voyeurism. People with HIV may be excluded from family and community events, and experience a loss of power and respect in the community. The effects may be akin to "social death". Verbal stigma and discrimination includes insults, taunts, blame, gossip and rumours. Institutional stigma and discrimination refers to differential treatment within an institution resulting in negative outcomes for the person with HIV. This may entail loss of livelihood and employment opportunities, housing and education. In a health care setting, it implies discriminatory treatment[7].

Health care-related stigma and discrimination is particularly damaging. Numerous studies document that health providers discriminate against people who are HIV positive[6,13,14,51-53] or those suspected of being infected. People may be denied services and/or medicines, passed from provider to provider, unnecessarily isolated, and tested for HIV or have their serostatus disclosed without consent. Providers also are not immune to stigma and discrimination that deter them from testing and care seeking and further erodes health system capacity.

People who experience HIV stigma and discrimination also may be affected by stigma associated with gender, sexuality, drug use, race, disability or other factors. Groups that typically experience multiple layers of stigma include injecting drug users, sex workers, men who have sex with men and prisoners.

Multi-layered Stigma

Multi-layered stigma magnify the effects of HIV stigma. Thus, stigma and discrimination tend to be most debilitating for people who are already socially excluded and who tend to be neglected in national

responses and by donors. Women, for instance, tend to experience greater stigma than men, are more likely to experience its harshest and most damaging forms, and have fewer resources for coping with the consequences[6,11,13]. Violence is a particularly harsh form of discrimination faced principally by women[53-57]. Women and girls report increased violence for requesting condom use, accessing voluntary testing and counselling, refusing sex within or outside marriage, or for testing HIV-positive[54, 59-65].

Multi-layered stigma increases the difficulty of meeting the needs of people most affected by the epidemic vulnerable to HIV[12, 66-70]. For instance, people who are already stigmatised are more likely than other people living with HIV to face discrimination, including refusal of services[9,40]. Also, internalised stigma is associated with depression, shame and isolation, and it often complicates health care seeking. Interventions should address multiple sources of stigma to better reach and serve already stigmatised groups.

TABLE 1.1: FACTS AND FIGURES ABOUT STIGMA AND DISCRIMINATION[1]

Prevalence	■ In China, a survey of more than 5,500 people found that 45 percent of those who ever heard of AIDS had a stigmatising attitude toward people living with HIV and AIDS[25]. ■ In a survey of people living with HIV in Tanzania, 56 percent reported experiencing some form of stigma and discrimination[13].
Physical, social, and verbal abuse and isolation	■ In Vietnam, 54 percent of people surveyed in Cai Khe and 21 percent in Quang Ninh said they would not buy food from a person suspected of being HIV+[40]. ■ In Senegal, a study of men who have sex with men found that 40 percent had experienced verbal abuse within their communities, and 13 percent had experienced physical abuse by the police[71]. ■ A national household survey in South Africa found that 20 percent of respondents said that HIV-positive children should be kept separate from other children to prevent infection[72].
Loss of housing or employment	■ In sample of people living with HIV in Tanzania, 43 percent lost access to a resource such as housing or employment[17]. ■ A South African survey of people living with HIV found that 27 percent of men and 18 percent of women reported that HIV caused them to lose a job or housing[72].

TABLE 1.1: FACTS AND FIGURES ABOUT STIGMA AND DISCRIMINATION[1]	
Differential treatment in institutional settings	■ In a survey of injecting drug users in Indonesia, 40 percent said stigmatisation was the reason why drug users avoided HIV testing[73]. ■ In India, a study conducted in three hospitals found 64 percent of health care providers had moderate stigma, while 24 percent had high stigma according to a stigma index. Higher stigma index scores were associated with a greater likelihood of discriminatory practices[48]. ■ In a survey of more than 1,000 health care professionals working directly with HIV patients in four Nigerian states, researchers found 59 percent believed patients with HIV and AIDS should be on a separate ward; 12 percent believed treatment of opportunistic infections wastes resources; 9 percent refused to care for a patient with HIV; and 43 percent observed others refusing to admit a patient with HIV into the hospital[74,75].

[1] Most evidence on stigma and discrimination is qualitative, especially evidence documenting the experiences of vulnerable groups. Information in Table 1 was culled from limited available sources. Thus, the data represent only a sampling of stigma's consequences.

Effect on the AIDS Response

Stigma and discrimination compromise prevention, disclosure, treatment and care efforts. With its potentially devastating consequences, stigma and discrimination represent a major "cost" for individuals in decision making related to preventive behaviour and to seeking treatment and care.

For people living with HIV, stigma and discrimination can be more difficult to cope with than the medical issues associated with HIV. In a survey of people receiving antiretroviral (ARV) therapy in Botswana, 37 percent of respondents said it was more difficult to cope with the social consequences of their HIV status than the medical ones, while 14 percent said they were equally difficult to handle[76].

> "Compared to people who had been tested, individuals who were not tested for HIV demonstrated significantly greater AIDS-related stigmas; ascribing greater shame, guilt and social disapproval to people living with HIV…"
>
> **—Study results on voluntary testing and counselling from Cape Town, South Africa[77]**

The high cost of being identified with HIV increases the likelihood that people will avoid getting tested, disclosing their status or seeking treatment and care. Even the widespread availability of treatment does not necessarily diminish stigma and discrimination and lead to greater testing and treatment levels. In 2002, Botswana became the first African country to launch a national antiretroviral treatment programme. Despite its commitment to universal access to treatment, enrolment in its Masa ARV Therapy Programme lagged. The government identified HIV stigma and discrimination as major barriers to participation[76, 77].

Lower Uptake of Preventive Services and Testing

Stigma and discrimination are associated with lower uptake of preventive services, including under- or non-participation in educational meetings and counselling[27]; lower intention to take preventive measures [24]; and reduced participation in programmes to prevent mother-to-child transmission[78,79]. In countries with markedly different epidemics, such as Jamaica and Zambia, researchers have found numerous instances where fear of stigma and discrimination deters people from getting tested[26, 79, 80]. In Botswana, a survey of patients receiving antiretroviral therapy found that 40 percent delayed getting tested for HIV, mostly due to stigma[53]. Health care workers interviewed in South Africa cited stigma as the most important reason why people in their communities do not get tested. Also, stigmatising beliefs—which perpetuate the notion that HIV only happens to others—keep people from testing[26].

Key populations at higher risk of HIV often face human rights violations that pose additional obstacles to prevention. One study of street-based sex workers in central Bangladesh found 60 percent reported being raped by police men in the previous year. Reports from sex workers suggest "most police" refuse to use condoms in these rapes[81]. Among injecting drug users, prevention efforts are confounded by the controversy surrounding needle exchange and drug substitution programmes[66].

Stigmatising attitudes are associated with denial of risk and a lower likelihood of adopting preventive behaviours[24]. One study among Chinese migrants found that those who held stigmatising beliefs toward people with HIV were more likely to have multiple sexual partners, a commercial sex partner and a sexually transmitted infection. Those with stigmatising beliefs also were less likely to use condoms or express willingness to be tested[82]. Similarly, a study of truckers in Brazil found that the higher someone scored on a scale measuring stigmatising attitudes, the lower the likelihood that they had an HIV test[83].

Reduced and Delayed Disclosure

Disclosure of serostatus is key for outcomes ranging from condom use to care seeking. Numerous studies have found stigma and discrimination adversely affect disclosure to partners, providers and family members[70, 76, 84-86]. A study among HIV-infected women in the United States found that as the level of perceived stigma and discrimination increased, the level of disclosure and psychological functioning decreased[47]. In China, a study found that patients with sexually transmitted infections who felt stigmatised were less likely to agree to notify their spouse[44]. A Tanzania study among persons living with HIV found only half of respondents had disclosed their status to intimate partners. Among those who disclosed, the average time from knowledge to disclosure was 2.5 years for men and four years for women[17].

Postponement or Rejection of Treatment, Care and Support

Researchers have connected stigma and discrimination with postponing or rejecting care, travelling outside local communities for care to prevent breaches of confidentiality, and lack of adherence to medicines [27, 28, 44]. In Botswana, programme managers reported that people often sought services only when they could no longer hide their symptoms. By then, they were desperately ill, well beyond the optimal stage for drug intervention[86]. Similarly, researchers found more than two-thirds of all newly diagnosed AIDS cases in Jamaica tested late in the progression of their illness, a phenomena linked to stigma. In the first half of 2002, around one-third of new AIDS cases in Jamaica were reported as deaths[70]. Stigma and discrimination may also compel people to conceal medicines, which may result in inconsistent doses. A study in South Africa found concealment strategies included grinding drugs into powder and not taking medicines in front of others[88].

Key groups, such as men who have sex with men and injecting drug users, often avoid or delay seeking needed services for stigma-related reasons. These include fear of being "found out"; discrimination by health workers; and, in some instances, incarceration and/or having their property taken away[71, 73]. In Jamaica, HIV workers have also experienced violence through their perceived associations with homosexuality and promiscuity[70].

Further Reading

Ogden, J. and L. Nyblade, *Common at Its Core: HIV-Related Stigma Across Contexts*. 2005, International Center for Research on Women: Washington, DC.

Parker, R. and P. Aggleton, *HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action.* Social Science & Medicine, 2003. 57(1): p. 13-24.

SECTION TWO: TALKING POINTS ON HIV STIGMA AND DISCRIMINATION

The following talking points summarise the key issues surrounding HIV stigma and discrimination.

Stigma and discrimination are globally damaging and prevalent.

For many people living with HIV, stigma is a form of social "death" and is economically devastating.

- A positive HIV test can be socially and economically devastating: job loss, school expulsion, violence, social exclusion, loss of property, denial of medical services, and lack of care and support.
- Stigma and discrimination are a daily reality for those living with HIV and their families. It also affects groups closely associated with HIV, including sex workers, men who have sex with men, injecting drug users, prisoners and people who have tuberculosis.
- Stigma and discrimination exist in widely varying contexts and in settings with low and high HIV prevalence.
- Stigma and discrimination operate at multiple levels: within families; communities; institutions, such as health care facilities and places of employment; in the media; and in government policies.

> "Sometimes it is not the disease that kills…it is the bad words and remarks from people."
>
> **—urban male, Zambia**

- Stigma tends to heighten existing prejudices and inequities. Women and other vulnerable groups often experience its harshest and most damaging forms, including violence and denial of health services. At the same time, these groups have the fewest resources for coping with the consequences.

Stigma and discrimination compromise effective responses to HIV and AIDS.

People living in fear and denial are less likely to adopt preventive behaviour and access services.

- Stigma and discrimination confound efforts in HIV prevention, treatment, care and support. Because stigma and discrimination have such far-reaching negative consequences, people avoid behaviour that associates them with HIV.
- Fear of stigma and discrimination makes people less likely to adopt preventive behaviour, less likely to get tested, and less likely to disclose their HIV status to intimate partners and caregivers. Disclosure is critical for outcomes such as condom use and care seeking. Yet where stigma is widespread, people may wait four or more years before disclosing their positive status to a primary sexual partner.

- Stigma and discrimination are connected with postponing or rejecting care, travelling outside local communities for care to prevent breaches of confidentiality, and non-adherence to medicines. People will miss doses of their medicine rather than be "found out" as HIV positive. Some will seek treatment only when they can no longer hide their symptoms. By this point, they may be desperately ill, well beyond the optimal stage for drug intervention.
- Health providers often discriminate against people who are HIV-positive or whom they suspect are seropositive. People living with HIV may be refused services, denied medicines, passed from provider to provider, and tested or have their serostatus disclosed without consent.
- Groups such as sex workers, men who have sex with men and injecting drug users face additional barriers in accessing services, including criminalisation. Police harassment and violence also may deter prevention. Use of punitive responses (e.g., incarceration) rather than harm-reduction approaches (e.g., condom promotion, needle exchange) further undermines efforts to reach vulnerable groups.
- Stigmatising attitudes are damaging. People who stigmatise tend to dissociate themselves from any risk of HIV and are less likely to adopt preventive behaviours.

Slow response to stigma and discrimination hampers progress against HIV.

Neglecting stigma and discrimination impedes efforts to arrest the HIV pandemic.

- Despite its centrality, stigma and discrimination are neglected in most country responses. Reasons include a lack of understanding about how to take practical action, and a perception that these issues may be too complex to address. Services for socially excluded groups also tend to be controversial.
- The need for action on stigma and discrimination is globally recognised: UNAIDS, the World Bank, the G8 countries, and others recommend a more concerted, robust response to stigma and discrimination. The 2006 U.N. General Assembly calls stigma and discrimination crucial to combating HIV.
- As countries expand access to services, including antiretroviral treatment, the need for effective action against stigma and discrimination is more pressing. Even where crucial HIV services are available, uptake is often lower than desired due to stigma and discrimination.
- UNAIDS has recently categorised stigma, inequity and the abuse of human rights as one of four primary obstacles to scaling up services in HIV and AIDS.

Effective action is possible.

Strategies and tools for mitigating stigma and discrimination exist.

- Stigma and discrimination are often enforced at the family, community, institutional, and legal and policy levels. The most effective response to stigma and discrimination will operate at more than one level, focus on more than one target group and employ multiple approaches.

- Stigma is consistent across different contexts in forms, consequences and drivers. Practitioners can apply a common core response to stigma and discrimination with minor modifications across different settings.
- Principles for challenging stigma and discrimination include:
  - Creating an awareness of what stigma is and the benefits of reducing it;
  - Fostering motivation for change;
  - Addressing fears and misconceptions about HIV transmission;
  - Discussing topics considered "taboo"; and
  - Providing the skills to challenge stigma and change behaviour.

BOX 2.1: KEY ANTI-STIGMA ACTIONS

- Empowering people living with HIV and other vulnerable groups to know and assert their rights.
- Enlisting public figures, including religious leaders, to advocate against stigma and discrimination.
- Promoting laws that protect the rights of people living with HIV and other vulnerable groups.
- Supporting community-based efforts that foster critical thinking and inspire behaviour change.
- Promoting anti-stigma initiatives among health care providers, police, the judiciary, journalists, and educators.

- Multiple examples of promising approaches exist for preventing and reducing stigma among different groups, challenging discrimination, particularly in institutional settings, and promoting, protecting and fulfilling human rights.
- Promising interventions often combine empowerment of people living with HIV; education; and activities that promote interaction between people living with HIV and AIDS and different audiences. Participatory workshops also have led to attitude and behaviour change among different audiences.
- In health care settings, interventions using assessment tools and education have tackled discrimination in service access, testing and counselling, confidentiality, infection control, and quality of care.
- Proven anti-stigma and discrimination tools are available. Workshops using exercises from the toolkit, *Understanding and Challenging HIV Stigma*, have been effective with decision makers, community members, journalists, health providers and others.
- Stigma and discrimination are measurable. Standard indicators for monitoring and evaluation exist.

Reducing stigma and discrimination is important for U.K.'s HIV strategy.

Action to arrest stigma and discrimination is closely aligned with the U.K.'s priorities and rights-based approach to HIV.

- The U.K. has played a key role in supporting innovative approaches to tackling stigma and discrimination and catalysing greater action internationally.
- DFID supports about 100 projects and programmes addressing HIV stigma and discrimination. These efforts span three major approaches, including preventing and reducing stigma, challenging discrimination, particularly in institutional settings, and promoting and protecting human rights.
- Specific DFID-supported activities include education and awareness campaigns, empowering excluded groups to advocate for improved services, and mobilising role models to foster openness and respect.

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SECTION THREE: CASE STUDIES OF PROMISING INTERVENTIONS

This section describes examples of promising interventions that are broadly representative of different approaches to stigma and discrimination reduction. These case studies showcase activities directed at policymakers, the judiciary, journalists, health providers, institutions and communities.

Case Study:

Vietnam's Comprehensive Stigma-Reduction Effort

PROGRAMME: Reducing HIV and AIDS-related Stigma and Discrimination

LOCATION: Hanoi, Quang Ninh and Can Tho provinces, Vietnam

IMPLEMENTING ORGANISATIONS: Institute for Social Development Studies (ISDS) with technical support from the International Center for Research on Women (ICRW)

Background

Amid a rapidly escalating HIV epidemic, Vietnam is trying to cope with growing demands for care and support. According to UNAIDS, the estimated number of people living with HIV more than doubled, from 122,000 to 280,000, between 2000 and 2006. With HIV widely viewed as a "death sentence" and a "social evil," stigma poses a serious obstacle to managing the epidemic. One woman living with HIV reported, "There was a girl who got the disease. She was abandoned, lying alone until death. No one visited or brought food or drink for her. Her parents left rice for her but would not come close to her."

Intervention

From 2002 to 2007, this project undertook research to identify drivers of stigma and designed a strategy to tackle stigma and discrimination from multiple angles. Researchers found high levels of fear, avoidance and blame. One man living with HIV observed that people perceive leprosy and HIV "[as] equivalent, so they keep away". HIV's associations with intravenous drug use and sex work have made stigma particularly severe. One man who participated in a focus group explained, "…people are generally aware of [HIV and AIDS]. They are aware that this is a social evil, it is not a disease." Moreover, researchers found that policies and media coverage reinforced these attitudes by fostering perceptions of HIV as a "social evil".

In response, the Institute for Social Development Studies, in collaboration with ICRW, designed a project to tackle stigma and discrimination in policy, the mass media and communities. The project sites include the central level in Hanoi and two provinces: Quang Ninh and Can Tho. The activities address fear of casual transmission; the association of HIV with "social evils"; and sensationalised, inaccurate and fear-based media coverage.

Project activities span the national policy level, the provincial level and the community level. At each level, participatory exercises from the toolkit, *Understanding and Challenging HIV Stigma*, encourage critical thinking and inspire action. Activities at the national and provincial levels provide broad-based support for intensive community efforts. Communities devise anti-stigma and discrimination plans of action with facilitation by project staff. Community activities include competitions for writing, drawing, song and drama; formation of new volunteer groups of people living with HIV; compilation and distribution of HIV stigma stories and experiences; and mobile information, education and communication efforts. Community work culminates in a Unity Day celebration that showcases activities.

Results

Project activities changed attitudes among decision makers, reporters, community members and others. Activities also catalysed anti-stigma and discrimination action at the national, provincial and community levels. After participating in sensitisation workshops, national party officials requested media guidelines for less stigmatising portrayals of people living with HIV. Working closely with government partners, the project team formulated anti-stigma and discrimination guidelines for media and communications. These have been widely disseminated to reporters, practitioners, creators of public awareness campaign materials, and others who are responsible for conveying information about HIV and other health topics to the general public. In addition, project activities with journalists have resulted in numerous television programmes and press articles countering stigma and dispelling myths about people living with HIV. Over the course of a year, stakeholders in the study communities developed and implemented a broad array of anti-stigma and discrimination programming. Evaluation results from these activities will be available fall 2007.

Lessons Learnt

Project experiences suggest several key lessons:

- Working with policy-makers is key for an "enabling" environment and rapid community-level progress. The project quickly gained community-level traction as enthusiasm grew among national and provincial decision makers. Additionally, policy-makers who participated in sensitisation activities arranged for new guidelines for AIDS reporting and communications. These guidelines will help ensure stigma reduction continues after the project ends.
- Participatory methods foster understanding and action among different audiences, from policy-makers to journalists to community members. After participating in workshops, for instance, journalists produced more accurate, less sensational stories on HIV and AIDS. Journalists also developed eight television programs on stigma and discrimination.
- Factual material is necessary, but not sufficient. Fears of casual transmission, for instance, are not easily allayed. While a project fact sheet was well received, fears remained. For readers, one especially troubling question was how long HIV could survive in the environment outside of a host. The fact sheet stated that HIV "dies quickly" upon exposure to air, but people were anxious to know exactly how quickly in terms of seconds, minutes or hours. This points to the importance of dialogue and interaction in stigma and discrimination reduction.

For more details, please see: Hong, Khuat Thu, Nguyen Thi Van Anh, and Jessica Ogden. *Understanding HIV and AIDS-related Stigma and Discrimination in Vietnam*. Washington, D.C.: ICRW, 2004.

Case Study:

Mobilising Leaders in the Caribbean through Champions for Change

PROGRAMME: Champions for Change

LOCATION: Caribbean region

IMPLEMENTING ORGANISATIONS: Caribbean Community (CARICOM) and Pan Caribbean Partnership Against HIV/AIDS (PANCAP)

Background

The Caribbean, which is second in HIV prevalence to sub-Saharan Africa, is intensifying its efforts to contain the epidemic. High stigma levels and widespread homophobia, however, confound programme efforts. As a practitioner from the Cayman Islands reported, "An HIV positive man stopped collecting his ARV drugs from the hospital pharmacy because it was reported to his family that he was seen there every week. He also resigned from his job when offered a promotion because the higher position required him to undergo a medical examination that included an HIV test."

Intervention

Champions for Change—a joint initiative supported by DFID, CARICOM and PANCAP— addresses stigma and discrimination by engaging public figures who are leaders in their communities to be "champions" in changing attitudes. The programme originated at the highest levels of government. During a 2003 meeting, Prime Ministers Tony Blair and Dr. Denzil Douglas of St. Kitts and Nevis agreed on the need for a conference to mobilise action against stigma and discrimination. In 2004, St. Kitts hosted the first conference in the region to enlist "champions" to advocate for social change in the Caribbean.

Using high-profile conferences, the programme mobilises leaders to tackle stigma and discrimination. Conference proceedings involve education, engagement with people living with HIV, action toolkits, and group declarations and commitments. The conferences are designed to jump-start the process of changing attitudes and values by promoting advocacy among leaders. These meetings provide a tangible demonstration that reducing stigma is endorsed at the highest levels. In addition, through plenary sessions and working groups, the conferences challenge the fears, biases and misconceptions of participants. Testimonies of people living with HIV heighten the impact of proceedings.

The first conference brought together a wide cross-section of community leaders. It provided a forum for influential people from politics, media, religion, sports and other areas to engage directly with people living with HIV and AIDS. The conference highlighted the need for stigma and discrimination reduction to figure more prominently in programme efforts, especially as it cuts across prevention, care and treatment activities. The conference's plan of action helped shape PANCAP's Caribbean Regional Strategic Framework.

The first conference also highlighted the unique potential of faith-based organisations to inspire change. The second Champions of Change conference was held specifically for faith-based leaders. It identified ways they could address causes, such as homophobia, and mitigate stigma's effects. An Executive Committee developed an implementation guide for the short- and medium-term strategies contained in the plan of action from the conference. The programme also created a database of champions within faith-based organisations and secured pledges from conference participants for specific stigma-reduction action.

Implementation guidelines were translated for use throughout the region. Various faith-based groups have subsequently used the guidelines to initiate local programmes. Additionally, implementation included training for faith-based organisations providing home-based care for people living with HIV.

The third conference, held in Barbados in 2006, engaged the mass media in reducing stigma and discrimination. The conference brought together regional decision makers, practitioners in the media and technical specialists in HIV and AIDS. The conference examined reasons for the existing stigmatising coverage and identified best practices to change this, considering the potential of new communication technologies. These and other proceedings culminated in a plan of action and the framework for an anti-stigma toolkit for the media.

A media "champion" from a local television station CNS Television has since gone on to air HIV programming on a regular basis. The station's "Voice of the People" programme has publicised discriminatory practices against people affected by HIV. Additionally, during coverage of World Cup Cricket, the channel included an interview with former West Indies World Cup cricket captain Clive Lloyd, who discussed how sports personalities could help fight HIV stigma and discrimination.

Results

DFID has commissioned a full external evaluation of Champions for Change. The evaluation showed that the Champions for Change process had made a real difference in the region, but the organisers could have paid more attention to the follow-up activities, supporting those who became champions in a more structured manner. DFID and KfW are now working with PANCAP to fund a regional unit designed to tackle HIV stigma and discrimination and support those who are working to reduce the problem.

Lessons Learnt

Project experiences suggest several key lessons:

- The involvement of people living with HIV from the outset was crucial to successful planning and implementation. Their participation helped develop new working relationships in sub-regions and countries. Additionally, their participation strengthened the impact of the conference since many senior-level attendees had never had "face-to-face" dialogue with anyone directly affected by HIV.
- Mobilisation activities such as the Champions for Change conferences are most effective when designed to target specific groups and catalyse actions unique to that group. By focusing on specific groups such as faith-based organisations and the mass media, the plans of actions emanating from Champions of Change conferences are more manageable and feasible.
- An action orientation is critical. Conference attendees were invited based on their commitment to take subsequent action.
- Conference activities have fostered awareness, networking and action. But knitting the initiative's varied activities into a unified, harmonised whole is also important for longer-term impact. A central organising entity can fulfill this role. PANCAP has proposed a stigma and discrimination unit to provide a stronger infrastructure for the initiative. In general, PANCAP's coordinating role, local leadership and organising have been crucial to success.
- Other factors important to post-conference action include products such as toolkits and networking at events. The initiative has developed a toolkit that helps individual champions play a more effective role over time. Support and teamwork, fostered by the conferences, are also key. Often, people working together can better overcome obstacles and opposition than individuals working alone.
- Mobilisation activities such as conferences are not an end in and of themselves. They should be seen as part of a broader strategy to reduce stigma and discrimination.

For more details, please see: PANCAP Coordinating Unit, CARICOM Secretariat, *The Champions for Change Process: Tackling Stigma and Discrimination in the Caribbean Region*. May 2007.

Case Study:

Combating Health Care Discrimination in India

PROGRAMME: Reducing Stigma and Discrimination in Health Care Settings

LOCATION: New Delhi, India

IMPLEMENTING ORGANISATIONS: SHARAN, India, with technical assistance from the Horizons Program (led by Population Council with other partners)

Background

For people living with HIV, stigma and discrimination in a health care setting can mean the difference between life and death. In India, researchers found people living with HIV were subjected to sub-standard treatment and refusal of services. According to one person living with HIV, "We are often refused treatment in hospitals. They tell us, 'we have no empty bed.'" Another person living with HIV noted, "The doctor refused to examine me for almost two months." Researchers found other serious breaches of humane treatment, including segregation and labelling of HIV-positive patients, disclosure of a patient's serostatus to family without his/her consent, and lack of HIV post-test counselling.

Intervention

Using a "PLHA-friendly" checklist and other means, a project undertaken by SHARAN and the Horizons Program found discrimination can be reduced in a health care setting. The project has not only resulted in improved access and service delivery for people living with HIV, but a safer working environment for health workers.

The project began by examining the factors that contribute to discrimination in three New Delhi hospitals. The project team found that multiple factors contribute to negative and differential treatment of patients living with HIV: staff prejudice against HIV-positive people or those perceived to be at risk of HIV; staff misconceptions about HIV transmission through casual contact; lack of hospital policies protecting patients; and inadequate staff training on infection control.

The project team met with managers from each hospital to discuss the findings. Using a participatory approach, the team worked with the managers and other hospital staff to help them assess how well their hospital serves people living with HIV and to identify realistic responses to address stigma and discrimination.

BOX 3.1: THE "PLHA-FRIENDLY" CHECKLIST

The checklist includes indicators to assess practices in five key domains:

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

Managers of health care settings may use the checklist as a self-assessment tool to identify how well their facility serves HIV-positive people and provides a safe environment for staff. The tool also assists managers to set goals for improvement. It may be applied to large hospitals, clinics or specific departments.

Results

Managers were initially reluctant to acknowledge problems in their facilities, believing that such things did not happen in "their" hospital. But facility-specific data helped convince them that changes were necessary. Also, using a "PLHA-friendly" checklist to assess the extent to which their hospital was free of

stigmatising practices spurred managers to set and meet action plan goals. These goals included establishing an HIV and AIDS care and management policy; enlisting local AIDS nongovernmental organisations to sensitise and train health workers about HIV transmission; strengthening HIV counselling as part of HIV testing; and developing and disseminating information on infection control procedures and the availability of post-exposure prophylaxis to staff.

These efforts translated into improved attitudes by health workers, as measured by surveys administered before the intervention activities began and about two years later. For example, the proportion of health workers who were categorised as having the least stigmatising attitudes toward people living with HIV more than doubled from the first survey to the second (12 percent vs. 27 percent) and those with the most stigmatising attitudes declined considerably, from 24 percent to 7 percent. The surveys also revealed large increases in knowledge about HIV transmission and some improvements in reported practices over time. The intervention also improved health workers' understanding and practice of universal precautions, including the use of gloves while drawing blood, and resulted in fewer reports of a lack of infection control supplies.

These changes were corroborated by interviews with hospital managers. According to one nursing supervisor, "Patients are lying next to each other [not segregated]. Other patients do not know each other's disease. No one is refused care and treatment in this hospital." A doctor and head of a department commented, "There has been a decline in stigma associated with AIDS, as there has been a decline in the level of fear associated with this disease."

Lessons Learnt

Project experiences suggest several key lessons:

- Reducing HIV stigma and discrimination in health care settings requires not only addressing the attitudes and practices of health care workers but also meeting their needs for information, training and supplies to prevent occupational exposure to HIV.
- Policies and programmes to reduce stigma and discrimination must be directed at all hospital employees—from the cleaning staff to hospital superintendents—since everyone has a role to play.
- Outside groups wishing to work in health care settings to reduce stigma and discrimination need to position themselves as true partners rather than as critics or whistleblowers if their goal is to improve the health care environment for people living with HIV.
- With tools such as a "PLHA-friendly" checklist, hospital managers reviewed facility-specific information on stigma and discrimination and devised their own solutions. The stigma-reduction efforts were not imposed by the project. Hospital managers appreciated this approach.

For more details, please see: Horizons, SHARAN and Institute of Economic Growth, *Improving the hospital environment for HIV-positive clients in India: Findings from a pilot study on addressing stigma and discrimination in health care settings.* 2005, Washington, D.C.: Population Council.

Case Study:

Engaging Youth to Provide Care and Tackle Stigma in Rural Zambia

PROGRAMME: Involving Young People in the Care and Support of People Living with HIV and AIDS

LOCATION: Luapula Province, Zambia

IMPLEMENTING ORGANISATIONS: Horizons Program (led by Population Council), CARE International/ Zambia, and Family Health Trust.

Background

People living with HIV in rural communities often face a double burden: a lack of community care and support services, and stigmatising attitudes and behaviours from family and community members. A project in Zambia implemented by the Horizons Program and local partners found that training youth to be adjunct family caregivers not only filled an important gap in service delivery, but contributed to a reduction in stigma in the communities where they worked.

Intervention

The project took place in Luapula Province in Northern Zambia, a remote area located more than 800 km from Lusaka. In the province, as throughout Zambia, school- and community-based anti-AIDS clubs promote HIV prevention to youth. The project team sought to find out whether club members could also be trained to provide care and support services to people living with HIV in the community. If so, the project aimed to learn how these services would be perceived and whether they would help reduce household- and community-level stigma.

To evaluate the project, the researchers selected 30 anti-AIDS clubs from two communities in Luapula Province to receive training on HIV prevention, club management, and care and support. An additional 30 anti-AIDS clubs from two communities in Northern Province, a similarly rural area, only received training on HIV prevention and club management. Club members from both provinces were interviewed before the training and about 18 months later. In addition, the project team talked with community members, including people living with HIV, to elicit their views about the program.

The extra training for Luapula club members focused on how to provide care and support to the family, including help with bathing; dressing wounds; housework; counselling; and how to network with existing community resources, such as NGOs, orphans and vulnerable children programs, health centres, and home-based care programs. Networking with these groups created opportunities for mentoring youth caregivers, helped identify households where youth caregivers could volunteer their time, and facilitated referrals by youth caregivers to other services for household members.

The project also provided kits to each club to help the youth caregivers treat sores and prevent infection (i.e., gloves, disinfectant, soap, cotton wool, gentian violet, bandages), document their experiences (i.e., pens and notebooks), and reinforce their group identity as youth caregivers (i.e., uniform aprons and badges). Each club also received two bicycles to help club members reach more isolated households.

Results

After analysing the data collected from club members and the community, the project team found that club members from Luapula Province were more likely to have provided care to people living with HIV in the household than those from Northern Province. By the follow-up survey, Luapula club members reported that they conducted one to two visits per week to families, with both females and males caring

for an average of four people living with HIV in the previous three months. Youth caregivers reported that they were most able to provide help with household chores, cleaning sores, counselling families about HIV and making clinic referrals. And people living with HIV who were interviewed reported satisfaction with these services.

Some clients also perceived profound positive changes in the attitudes and behaviours of family members over time. As a result of observing the activities of the young caregivers and interacting with them, family members began to get more involved in care giving themselves. According to one HIV-positive man, "Before my niece became a caregiver, I was isolated and abused by my sister, but now my niece has made her mother accept me." This man went on to report that after not having had any help to bathe for several months, he was finally given a bath by his mother and sister.

And at the level of the wider community, clients reported seeing changes among their friends and neighbours. After witnessing visits from the caregivers, community members began to see that they too could visit people living with HIV. As noted by someone living with HIV served by the program, "Our community is beginning to accept people with AIDS since youth caregivers started visiting; they are not as fearful as before."[44]

Lessons Learnt

Project experiences suggests several key lessons:

- The efforts of trained youth caregivers can lay the foundation for decreased isolation and stigmatisation of HIV-affected families. Regular care giving visits to households of people living with HIV by enthusiastic and trained youth can change community attitudes and decrease stigma.
- Youth caregivers can address the concerns of family members and build their capacity to provide care to people living with HIV and AIDS. Encouraging family members to provide care is important to the emotional well-being of people living with HIV and AIDS. When families provide care themselves, services are sustainable and stigma is likely reduced.
- Trained youth are able to meet a range of needs of people living with HIV and orphans and vulnerable children. But the limitations of caregiver capabilities should be clearly conveyed to clients. This will help avoid raising false expectations of receiving food or medicines or placing demands on caregivers that they are not equipped to meet.
- Providing ongoing monitoring and training to strengthen capacity and improve services is key. Youth caregivers may require psychosocial support to address stress. Support for ongoing monitoring and training can be enhanced by local partnership.
- Community involvement and partnerships are essential. Involving community leaders is vital to the acceptance, success and sustainability of the activities of youth caregivers. Partnerships with local institutions extend the scope of services beyond what youth alone can provide, legitimise youth caregiver services, and increase all partners' understanding of each other and the ways in which they can meet the needs of people living with HIV and their families.

For more details, please see: Esu-Williams, E., et al., *Involving Young People in the Care and Support of People Living with HIV/AIDS in Zambia,* in *Horizons Final Report.* 2004, Population Council: Washington, D.C.

Case Study:

Truckers in Brazil: Where the Rubber Meets the Road

PROGRAMME: Addressing the HIV Prevention, Testing, and Treatment Needs of Mobile Populations

LOCATION: Foz do Iguaço, Brazil

IMPLEMENTING ORGANISATIONS: Horizons Program (led by Population Council); Municipal Secretariat of Health, Foz do Iguaço

Background

Highly mobile populations like truck drivers who spend much of their time on the road are often challenging to reach with HIV-related services. Yet even when services are made available, truckers may shun them because of the stigma associated with accessing HIV-related information, testing and treatment. In fact, truckers crossing the southern Brazilian border at Foz do Iguaçu commonly reported that society was prejudiced against them because they were blamed for being vectors of diseases such as AIDS, therefore they didn't want to be seen accessing "AIDS" services.

Intervention

Taking these perceptions of stigma into account, the Horizons Program, in collaboration with local Brazilian partners, including the Municipal Secretariat of Health, designed and implemented a multifaceted intervention for truckers that proved to be non-stigmatising and effective in reducing HIV risk and increasing uptake of HIV testing.

The project began with focus group discussions and in-depth interviews with truckers, sex workers and customs officials to learn more about HIV risk among truckers. The research found that truckers were often required to remain in the customs area for two to three days until documentation was completed. A booming commercial sex area existed directly in front of the station; however condoms were not easily available.

In response to these findings, the project decided to offer services inside a trailer parked in the customs area. In addition to voluntary testing and counselling for HIV and syphilis, and syndromic management of sexually transmitted illness (STI), the project's health staff would also provide preventive health services, such as blood pressure and diabetes screening. Thus truckers who entered the trailer would not automatically be associated with an HIV intervention; yet they would be exposed to HIV and STI information, services and condoms.

To evaluate the intervention, the project team conducted interviews with a random sample of male truckers passing through Foz do Iguaçu and a comparison border town (Uruguaiana) before the services were in place (n=1,775) and 18 months later (n=2,408).

Results

Data show that the intervention has been successful in reaching a substantial proportion of truckers: about half who gave follow-up interviews in Foz do Iguaçu participated in the intervention. A third report accessing voluntary testing and counselling and an additional 22 percent participated in educational talks or received educational materials or condoms. Service statistics collected during the 18 months of the intervention indicate that the intervention reached thousands of truckers with information and services.

The program was also successful in improving tested levels. Before the intervention, less than half of respondents in both sites had ever had an HIV test. At follow-up, the proportion of truckers who had ever tested for HIV increased by 49 percent in Foz do Iguaçu but it only increased by 15 percent in Uruguaiana, the site where there was no similar intervention. In the Foz do Iguaçu trailer, about 2,000 truckers received pre-test counselling for HIV and syphilis, 1,795 gave a blood sample, and of these, 1,492 (83 percent) returned 15 days later for their results and post-test counselling over the 18-month period.

Other data show an increase of 21 percent in ever use of condoms with an occasional partner among truckers in the intervention group over time, but a 3 percent decrease in the comparison group. There was no change in condom use with sex workers in either group, but rates were already high at the start of the intervention.

Almost all survey respondents rated the services as "great" or "good." One of the main reasons for high levels of satisfaction was that the services were not only for HIV and sexually transmitted infections, but also for common diseases. Respondents also liked that the services were easily accessible; the educational messages were useful; and they were treated in a confidential, non-stigmatising way by the health workers. According to one Paraguayan trucker, "I really loved the way I was treated… the nurses and all the health workers are very helpful and kind… they know how to treat people."

The operation of the health services has been transferred to a local university, which will continue providing them free of charge, and will likely broaden the scope of services offered.

Lessons Learnt

Project experiences suggest several key lessons:

- To minimise AIDS-related stigma against a mobile population such as truckers, a range of basic health services should be provided and be strategically placed for easy access.
- It is essential that high quality, confidential care be offered by attentive staff free of stigmatising attitudes. This was key for attracting truckers.
- Sustainability of activities may be achieved through creative partnerships such as that with a local university.

For more details, please see Díaz, Juan, Magda Chinaglia, Sheri Lippman, Julie Pulerwitz, Cristina Ogura, and Maeve Mello. "Addressing the HIV prevention, testing, and treatment needs of mobile populations: Focus on truckers in Brazil," Horizons Research Update. Washington, D.C.: Population Council. October 2006.

Case Study:

Transforming Approaches Toward Injecting Drug Users in China

PROGRAMME: China-U.K. HIV and AIDS Prevention and Care project (HAPAC)

LOCATION: Sichuan and Yunnan provinces, China

IMPLEMENTING ORGANISATIONS: Chinese partners at national level, Sichuan and Yunnan provinces, DFID staff, Family Health International, Futures Group

Background

In China, HIV is spreading most rapidly among injecting drug users. According to UNAIDS, this group now accounts for nearly half of the estimated HIV cases in the country. With many users still sharing needles and syringes, infections will continue to rise without more effective interventions.

Even with the epidemic largely concentrated among injecting drug users and other vulnerable populations, programmes for these groups are often contentious. Vulnerable populations are widely associated with behaviours considered morally objectionable. In many settings, this means HIV support is directed primarily toward the general population rather than the groups at most risk of HIV. In China, coverage of needle-syringe exchange programmes and drug substitution therapy has been especially inadequate. Traditional approaches to injecting drug users typically involve arrest, detention, detoxification and "re-education."

Intervention

DFID has transformed approaches to injecting drug users and other vulnerable populations in China. Recognising that a primary barrier to a more effective response was political, DFID combined demonstration projects with training, technical assistance and study tours for government officials, which facilitated policy dialogue. In doing so, DFID has demonstrated the practicality of introducing effective prevention programmes for injecting drug users and other vulnerable groups.

In China, DFID has supported pilot interventions among injecting drug users, sex workers, prisoners and men who have sex with men. This work has influenced political leadership on HIV and is credited with helping shift official views concerning these populations. The efforts among injecting drug users have resulted in particularly dramatic shifts in policies and practices. Supported activities include:

- Needle exchange and drug substitution demonstration projects;
- Study tours for Chinese officials to observe HIV prevention activities for injecting drug users in other countries; and
- Training and technical briefings for decision makers and practitioners on targeted HIV prevention methods.

Results

Activities have led to expanded efforts in prevention and treatment among vulnerable groups. After initial resistance, the Ministry of Public Security has welcomed the harm-reduction approaches piloted by DFID. The ministry is actively publicising and promoting needle exchange and methadone replacement therapy. The DFID-Global Fund China HIV and AIDS Programme (2006-2011) will scale up interventions for vulnerable groups to seven provinces and introduce treatment for people living with HIV, with an emphasis on injecting drug users and sex workers.

Working in a setting where development assistance is a tiny fraction of GNP (<0.07 percent), the U.K.'s support has been nevertheless hugely influential. The China experience indicates that projects, good quality technical assistance, well-designed pilots and policy dialogue can be enormously effective. Moreover, DFID achieved this with a relatively small amount of funding and modest constraints on human resources. Without restrictive policies, DFID has a major comparative advantage over other donors in supporting efforts for vulnerable groups. When a primary barrier to a more effective response is political—as in the case with prevention services for injecting drug users—even relatively modest support levels can result in large changes in national priority setting.

Lessons Learnt

Project experiences suggest several key lessons:

- A combination of pilot projects, policy dialogue and strategic technical assistance to maximise impact can be highly effective in inspiring political leadership and programmatic change, in particular on contentious issues such as harm reduction.
- This approach can be used both in settings where development assistance is limited and where it amounts to a large fraction of GNP. Where DFID provides budget support, this approach can ensure that appropriate HIV and AIDS interventions are delivered to key populations at risk of exposure to HIV.
- Pilot projects can provide the evidence to help officials see the real changes and benefits of HIV prevention programmes for key populations.
- Where harm-reduction approaches are unfamiliar and controversial, intensive training, technical assistance and study tours from the onset can help to change the mindset at the local and national level.
- A team approach emphasising joint learning can be useful in successfully introducing new programming. The China programme brought together UNAIDS and Ministry of Health for the pilot project monitoring missions to jointly learn and identify issues. This proved more effective than an "inspection-style" approach.

For more details, please see: DFID, *Taking Action Implementation—Focus on Women, Young People and Vulnerable Groups*. Pgs. 89, 102, 103; DFID, *Taking Action Implementation—Funding HIV and AIDS through "Country-led" Aid Instruments*. Pgs. 57, 65, 66; DFID, *Taking Action Implementation, Annex 3: Summaries of Country Case Studies: China.*

Case Study:

I Am HIV Positive: Empowering People Living with HIV in South Africa

PROGRAMME: Treatment Action Campaign

LOCATION: South Africa

IMPLEMENTING ORGANISATION: Treatment Action Campaign

Background

South Africa has one of the world's largest numbers of people living with HIV, but denial and delay have marked the government's response to the epidemic. In the late 1990s, when countries such as Brazil were offering large-scale treatment programmes, South Africa took no steps to make essential medicines widely available. Most South Africans viewed HIV as a death sentence and were either unaware of treatment or saw it as hopelessly out of reach.

In 1998, the death of Simon Nkoli, a long-time AIDS and gay rights advocate, showcased a terrible inequity: thousands of people with HIV were dying even while life-saving treatment was available to wealthy South Africans. Another death in 1998, that of AIDS activist Gugu Dlamini, demonstrated the intense stigma and prejudice associated with HIV. After publicly disclosing that she was HIV positive on World AIDS Day, Dlamini was beaten to death by her neighbours.

Not until 2003, and under much pressure, did the South African government announce a national treatment plan. Even still, denial continues to pervade the highest levels of political leadership, including President Thabo Mbeki and Health Minister Manto Tshabalala-Msimang.

Intervention

In response to a government in denial and the new availability of antiretroviral treatment, South African AIDS activists established the Treatment Action Campaign (TAC) on International Human Rights Day in 1998. Those joining TAC took a "Pledge to Save Lives" of people living with HIV. The group's goals were to make essential medicines available to all South Africans that needed them, and to educate people living with HIV and others about treatment and care.

TAC takes a distinctly rights-based approach to its goals. In the words of the group's national secretary, Mark Heywood, TAC campaigns "…have always been explicitly in pursuit of the realisation of constitutional rights to life, dignity and health care services." Toward these ends, TAC has cultivated a new cadre of grassroots activists and campaigned for change using court actions, civil disobedience, marches on Parliament, media relations, awareness-raising material, and treatment literacy and provision. In its efforts, TAC has recognised the importance of addressing stigma. Heywood writes, "…For a community-based AIDS activist movement to emerge and successfully demand access to treatment it was necessary for it also to confront the multi-layered problems of stigma and denial that exist first and foremost in communities, and are much more suffocating and dangerous to the poor than to the middle class."

Perhaps the group's best-known effort against stigma is a t-shirt with "HIV Positive" emblazoned on the front. TAC members first donned the t-shirt in response to the beating death of Gugu Dlamini. The t-shirt featured a photo of Dlamini, and the words, "Never Again," on the back. TAC has since developed other versions of the t-shirt, which has become its trademark and a proud badge of activism.

The t-shirt, which Nelson Mandela has worn on various occasions, is credited with helping de-stigmatise HIV. A deceptively simple device, the t-shirt nevertheless conveys a bold message about the importance of

openness and honesty in addressing HIV. In this way, it helps tackle denial, shame and silence. As people who are not HIV-positive also wear the t-shirt, it has come to represent solidarity with all those infected and affected by HIV.

The organisation's efforts have challenged stigma and discrimination in other ways as well. With one of its founders, Zackie Achmat, openly living with HIV, the group has created a model for HIV-positive leadership. And participation in the group is credited with helping members tackle internalised stigma and overcome social pressure to hide their illness. As one activist remarks, "I would be dead by now if it wasn't for TAC—they gave me the courage to accept my status and be open about it." By engaging in awareness-raising and education activities, the group challenges the ignorance and myths that perpetuate stigma and discrimination.

The group's many legal victories, facilitated through a successful partnership with the AIDS Law Project, have further empowered those living with HIV. Using the progressive democratic and legal systems of South Africa, TAC has fought and won human rights cases for persons living with HIV. According to one TAC organiser, its victories have made members aware of their ability to effect change on a national and global scale.

Results

The group is credited with a number of notable achievements, including:

- Obtaining lower prices for antiretrovirals and other essential drugs. In 2001, as a "friend of the court," TAC helped force the Pharmaceutical Manufacturers Association to drop its case blocking access to generic medicines, including antiretroviral treatment, in South Africa.
- Compelling the government to provide prevention of mother-to-child transmission programmes (2001) and to provide highly active antiretroviral therapy and other essential medicines through the public health care system (2003).
- Increasing understanding of HIV and its treatment among the public and health providers, stimulating demand for treatment, and dispelling the idea and acceptance of HIV as a "death sentence."
- Helping destigmatise HIV. Engaging former president and icon Nelson Mandela in wearing the "HIV Positive" t-shirt and disclosing his son's death of AIDS has provided a powerful role model for openness. TAC's efforts connect openness and honesty with the "moral high ground."

Lessons Learnt

Project experiences suggest several key lessons:

- An enabling legal environment can give stigma and discrimination-reduction efforts greater resonance and impact. In campaigning for rights and values already enshrined in South Africa's Constitution, TAC has succeeded in court, mobilised people across class and racial lines, and prevailed in the "politics of the moral high ground."
- Litigation can be groundbreaking in achieving rights, particularly when accompanied by vigorous public campaigns that help stimulate demand for the litigation.
- Engaging a leader and role model such as Nelson Mandela has been critical in terms of advancing openness and honesty regarding HIV, particularly in light of the lack of high-level government leadership.
- Giving greater voice, visibility and leadership to people living with HIV can help challenge stigma and foster hope, action and new beliefs about rights.

- Treatment literacy and other education efforts at the community level have been key in replacing prejudice with solid knowledge about HIV and its treatment.
- Partnerships have been critical to TAC's work. The legal support provided by the AIDS Law Project, for example, has been instrumental in its court cases.

For more details, please see: Boulle, J., and T. Avafia, *TAC Evaluation*, June 2005. www.tac.org.za/Documents/FinalTACEvaluation-AfaviaAndBoulle-20050701.pdf

Friedman, S., and S. Mottiar. A Moral to the Tale: The Treatment Action Campaign and the Politics of HIV/AIDS, 2004. Durban, South Africa: Center for Policy Studies, University of Kwazulu-Natal. www.nu.ac.za/ccs/files/Friedman%20Mottier%20TAC%20Research%20Report%20Short.pdf

Heywood, M. *The Price of Denial*. www.tac.org.za/documents/priceofdenial.doc. Heywood gave a presentation based on this paper at the XVI International AIDS Conference in August 2006.

UNAIDS. *HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes*. 2005. http://data.unaids.org/publications/irc-pub06/JC999-HumRightsViol_en.pdf

SECTION FOUR: ANTI-STIGMA TOOLS AND MANUALS

Tools and manuals are available for practitioners to use or adapt for anti-stigma and discrimination interventions.

TABLE 4.1: ANTI-STIGMA TOOLS AND MANUALS

	Description	Audience(s)	Countries of use	For more information
Toolkit				
Understanding and Challenging HIV Stigma	Toolkit consisting of 11 modules and more than 125 participatory exercises that can be used for participatory education interventions and workshops.	Broad range including: communities, community leaders, religious leaders, politicians, educators, service providers, journalists, people living with HIV and AIDS. New module for men who have sex with men.	Botswana, Côte d'Ivoire, Ethiopia, Ghana, India, Kenya, Mozambique, Nigeria, Senegal, Tanzania, Uganda, Vietnam, Zambia. Module for men who have sex with men developed in Senegal and Tunisia.	International HIV/AIDS Alliance: Supporting Community Action on AIDS in Developing Countries. www.aidsalliance.org
Targeted tools				
The truth about AIDS. Pass it on...	Web-based campaign toolkit includes: communications material, country case studies, harm-reduction guidelines, GNP+ resources (e.g., "Positive Development") and anti-stigma videos	National Societies of the Red Cross and Red Crescent	More than 120 national Red Cross and Red Crescent societies and their partners worldwide	International Federation of Red Cross and Red Crescent Societies www.ifrc.org/what/health/hivaids/anti-stigma/ The Campaign was produced in partnership with Global Network of People Living with HIV/AIDS.
Reducing Stigma and Discrimination Related to HIV and AIDS: Training for Health Care Workers	Consists of a participant's handbook, a trainer's manual and *Infection Prevention: A Reference Booklet for Health Care Providers*	Health workers	Bangladesh, Ethiopia, Ghana, India, Kenya, Nigeria, and Tanzania	EngenderHealth www.engenderhealth.org

TABLE 4.1: ANTI-STIGMA TOOLS AND MANUALS

PLHA-friendly Achievement Checklist	Toolkit to address stigma and discrimination in health care settings. Includes checklist to measure stigma and discrimination; *Hospital Guidelines for HIV/AIDS Care and Management*; and posters on infection control, waste management, and post-exposure prophylaxis.	Health care providers and hospital staff	Checklist endorsed for use by public hospitals throughout India, disseminated for use in Nepal and Tanzania	Horizons Project (Population Council) www.popcouncil.org/horizons
Called to Care	Three booklets (*Positive Voices; Making it Happen; and Time to Talk*) that raise awareness of HIV and reduce stigma within faith communities	Pastors, priests, religious sisters and brothers, lay church leaders, congregations	sub-Saharan Africa	Strategies for Hope Trust www.stratshope.org

SECTION FIVE: THE *UNDERSTANDING AND CHALLENGING HIV STIGMA* TOOLKIT

How is the *Understanding and Challenging HIV Stigma Toolkit* Organised?

Understanding and Challenging HIV Stigma is the most comprehensive toolkit available to address stigma and discrimination among different audiences.

The toolkit takes a participatory approach, providing a wide range of interactive exercises to help people understand stigma—what it means, why it is an important issue, its root causes—and develop strategies to challenge stigma and discrimination. Given its wide applicability and field-based content, the toolkit provides a cost-effective way for addressing stigma and discrimination. DFID staff can recommend that activities included in the toolkit be integrated into existing investments or used in a "stand-alone" effort. While the toolkit has been most widely used in sub-Saharan Africa, projects have successfully adapted it for use in India and Vietnam.

The toolkit, published in 2003, was developed with the active participation of more than 50 non-governmental organisations in Ethiopia, Tanzania and Zambia. It is divided into twelve chapters: an introductory chapter and 11 modules made up of educational exercises (see Table 5.1). The toolkit has been translated into a number of languages including Amharic, French, Portuguese and Swahili; adapted versions of the toolkit have been translated into Telugu and Vietnamese.

With a flexible menu of modules, the toolkit can be used to engage a range of audiences, including health workers, business leaders, educators, policy-makers and religious leaders. People affected by HIV stigma and discrimination can be both audience members and implementers of the toolkit. Knowing stigma from the "inside," this group can play an important role as trainers. At the same time they need help to cope with stigma, internalised stigma, and discrimination. One of the chapters in the toolkit, provides exercises for people living with HIV, aimed at strengthening their own understanding of stigma and discrimination and empowering them to challenge the situation. Support groups of people living with HIV could plan a series of weekly sessions based on these modules.

Since its release in 2003, the toolkit has been used in hundreds of workshops. Under the auspices of the International HIV and AIDS Alliance, an expansive "training-of-trainers" effort is ongoing throughout sub-Saharan Africa. Facilitators are using the toolkit in more than 10 African countries.

Drawing on these and other experiences, the Alliance brought together experienced practitioners from different countries to review toolkit exercises and produce new ones. An updated toolkit, drawing on the field experiences to date, was released in June 2007. The latest edition has separate sections for health workers, home-based care workers, youth workers and programmes supporting men who have sex with men. Additionally, researchers are crafting new material for workplace programs, faith-based organisations, gender programmes, schools and media workers.

TABLE 5.1: *UNDERSTANDING AND CHALLENGING HIV STIGMA* TOOLKIT

Module	Title	Target Group	No. of Exercises	Theme or contents
A	Naming the problem	General	9	Identify forms of stigma in different settings. Describe the forms, effects and causes of stigma. Build recognition that stigma exists and hurts people living with HIV, families, etc. and fuels the epidemic.
B	More understanding, less fear	General	6	Explore fears about getting HIV through casual contact. Discuss how these fears are based on inadequate understanding of HIV transmission; and how they lead to stigma as a form of rejection. Improve understanding on what it means to live with HIV and AIDS.
C	Sex, morality, shame and blame	General	12	Explore judgmental (shame and blame) attitudes that underlie stigma—the view that those who have HIV have been involved in "immoral behaviour". Relate this to feelings about sexuality and gender.
D	The family and stigma	General	11	Explores stigma and discrimination in a family setting—its forms and effects.
E	Home-based care and stigma	Home-based care workers	6	Exercises for home-based care workers—professionals and volunteers. Aim is to reduce stigma and discrimination within their working context.
F	Coping with stigma	People living with HIV	13	Strengthen people living with HIV by helping them overcome internalised stigma, cope with stigma, rebuild their self-esteem, and develop skills to take leadership roles in anti-stigma education and action.
G	Treatment and stigma	Health workers	12	Explores the ways in which stigma is a barrier to antiretroviral treatment, including adherence.
H	MSM and stigma	Men who have sex with men	7	Examines forms of stigma experienced by men who have sex with men and underlying causes, which are related to gender issues, judgments about morality and sexuality, and cultural and religious norms.
I	Moving to action	General	12	Reviewing the lessons learned and then applying them to one's own context. Participants develop action strategies and plan specific activities to challenge stigma and discrimination.
J	Children and stigma	Orphans and vulnerable children	21	Examines stigma and discrimination faced by orphans, street children, children living with HIV and other vulnerable children. Exercises for guardians help them understand the feelings of these children; and exercises for children help them deal with feelings and the impact of stigma.

TABLE 5.1: *UNDERSTANDING AND CHALLENGING HIV STIGMA* TOOLKIT				
K	Youth and stigma	Youth workers	16	Explores the stigma and discrimination faced by young people and how they are affected by judgements about age, morality and sexuality; the impacts of stigma on young people, including exclusion, isolation, dropping out of school, feelings of shame and thoughts about suicide; root causes of youth-related stigma and links between stigma, gender and sexuality; and strategies for coping with stigma. Exercises can be used with young people or with adults to help them better understand the stigma and discrimination faced by young people.

Session Plans and Workshops

The toolkit consists of detailed session plans for each of the exercises.

The session plans include: learning objectives, time, materials; a step-by-step description on how to facilitate the learning activities in a session, including a description of the methods used (e.g. pictures, drama/role playing, individual reflection, story telling, cardstorming, rotational brainstorming); questions for discussion; points to be emphasised in a summary at the end of a session; and action ideas for participants.

Using the toolkit, different workshops can be developed, for example;

A. Half-day workshop for Parliamentarians

B. One-day in-service training workshop for health workers

C. Two-day community workshop

D. Stigma education in the workplace (four weekly sessions, two hours each)

A. HALF-DAY WORKSHOP FOR PARLIAMENTARIANS

A1—Naming stigma through pictures

A2—Our experience of being stigmatised

A8—Forms, effects and causes—stigma problem tree

Action planning—Identification of forms of stigma and discrimination in different HIV services (e.g. ARV treatment, VCT, PMTCT, routine testing.) The task group then works to develop strategies to address stigma and discrimination in each of these settings.

B. ONE-DAY IN-SERVICE TRAINING FOR HEALTH WORKERS

Morning:

A1—Naming stigma through pictures

A2—Our experience of being stigmatised

B4—Fears about non-sexual casual contact

C2—Things people say about people living with HIV and others

Afternoon:

G1—Treatment and stigma: problem analysis

G2—Treatment and stigma in different contexts

I5—Mapping stigma in our institutions

I4—Problems solving and action planning

C. TWO-DAY COMMUNITY WORKSHOP

	Day 1	Day 2
Morning	A1—Naming Stigma through Pictures	B4—Fears about Non-Sexual Casual Contact
	A2—Our Experience of Being Stigmatised	D1—Stigma in the Family
	A4—Naming Stigma in Different Contexts	A8—Forms, Effects, and Causes (Stigma Problem Tree)
Afternoon	C2—Things People Say	Action Planning
	C5—Judging Characters	

D. STIGMA EDUCATION IN THE WORKPLACE (FOUR WEEKLY SESSIONS, TWO HOURS EACH)

Session 1:

A1—Naming stigma through pictures

A2—Our experience of being stigmatised

Action ideas:

a) Conduct stigma mapping in the workplace

b) Knowledge assessment—complete knowledge questionnaire on HIV/AIDS

Session 2:

Debrief stigma mapping and knowledge assessment

B4—fears about non-sexual, casual contact

C5—judging characters (character cards)

Action ideas:

a) Pass on new knowledge about HIV and AIDS to other workers.

Session 3:

D1—Stigma in the family

D4—Neighbours stigmatising neighbours

Action ideas:

Get more information about the workplace policies related to HIV and AIDS (e.g., availability of ARVs, discrimination, coverage for sickness, etc.)

Session 4:

Debrief data gathering on workplace policies

Action planning including mini-campaign to talk to other workers

Further reading

Kidd, R., S. Clay, and C. Chiiya, *Understanding and Challenging HIV Stigma: Toolkit for Action*. Second ed. 2007, Brighton: International HIV/AIDS Alliance, AED and ICRW. http://www.aidsalliance.org/custom_asp/publications/view.asp?publication_id=255

SECTION SIX: MEASURING RESULTS

Monitoring and Evaluation

Monitoring and evaluation is critical to determine if efforts to reduce stigma and discrimination are having the intended effects and what aspects need modification to improve results.

As stigma and discrimination efforts are starting to develop, careful evaluation can help identify effective models for replication and scaling-up. However, assessments of progress and impact are often neglected in anti-stigma and discrimination programmes. The following questions and considerations may prove useful in assessing proposed or monitoring ongoing interventions:

- **Does the programme include monitoring and evaluation of stigma and discrimination-reduction?**
- **Are the proposed indicators appropriate for what the programme seeks to accomplish?** In particular, what dimension of stigma is the programme seeking to change (e.g. fear of transmission through casual means, attitudes underlying stigma like homophobia) and will the proposed indicators capture that?
- **Does the proposed evaluation recognise that different dimensions of stigma and discrimination need to be measured separately?** An intervention may affect different dimensions of stigma and discrimination in different ways and at varying speeds. Inadequate measurement could lead to the conclusion that a programme is not working, when it is changing one aspect of stigma (e.g. fear), but not another (e.g. values).
- **Is the time frame realistic?** Do the proposed measures reflect what can be accomplished during the life of the programme? For example, a programme may propose to tackle stigma by addressing one or more underlying drivers (e.g. fear-related stigma). By doing this, the programme posits that it will lower avoidance and isolation of people living with HIV, thereby reducing fear of stigma and discrimination. The end result is an increase in uptake of HIV services like Voluntary Counselling and Testing (VCT). If so, what is the realistic level at which to measure success? Depending on the time frame and programme intensity, measurement could focus on any one or all of these indicators: reductions in the drivers of stigma; reductions in discrimination; reductions in fear of stigma; and increases in uptake of services. However, if the focus is on a level of indicator (e.g. uptake of services) that is unrealistic given the programme timeframe and focus, the risk is that a successful effort will be deemed unsuccessful.
- **Are the measures targeting the appropriate population?** If an intervention focuses on empowering people living with HIV, then measures should reflect these goals by assessing changes in internalised stigma and other aspects of empowerment. The measures should not, for example, focus on stigma and discrimination in the general population. On the other hand, interventions at the home, community or healthcare level will need to measure change in stigma and discrimination within these groups, and also assess the perspective of individuals who are interacting with or receiving services from these groups. Similarly, in assessments of media interventions, analysis of the content of messages themselves is important, but so is the effect of messages on the audience.
- **Lastly, are the proposed outcomes measurable?** Do they reflect the organisation's capacity in measurement? There are many levels at which monitoring and evaluation can be conducted. For example, measuring the impact of reductions of stigma and discrimination on outcome variables

such as uptake in services requires substantial investment and expertise. However, focusing on measuring reductions in the drivers of stigma, or discrimination, either through quantitative or qualitative assessment, can provide solid evidence of a programme's progress.

Indicators

Tested, reliable and validated indicators are now available to assess the underlying drivers of stigma and the extent of discrimination among communities, health providers and people living with HIV and AIDS. Examples include:

- The **PLHIV Stigma Index**. The International Planned Parenthood Foundation (IPPF), together with the Global Network of People Living with HIV/AIDS (GNP+), the International Community of Women Living with HIV/AIDS (ICW) and UNAIDS, has developed the "PLHIV Stigma Index". This Index is a tool by and for people living with HIV to document the stigma and discrimination experienced by HIV-positive people, including the presence of internalised stigma and the ability to safely disclose status and access care, support and treatment. Information is collected through a questionnaire structured around the different factors of stigma and discrimination. The Index can be used at different points in time to detect trends in the experiences of stigma and discrimination. The Index will be translated into different languages and will be free to use by groups and organisations globally. For more information contact Kevin Osborne, at KOsborne@ippf.org.
- Indicators for assessing the fear of contracting HIV through casual contact, value-driven stigma and the level of discrimination. These indicators are constructed using simple questions developed and field-tested by ICRW in Tanzania. Distinct questions have been developed to measure these three domains among the general population, health providers and people living with HIV and AIDS. A short list of tested indicators for the community level is outlined in Table 6.1. The complete list of indicators derived from this work can be found in *Measuring HIV Stigma: Results of a Field Test in Tanzania* (see *Further Reading* for citation).

TABLE 6.1: ASSESSING STIGMA AT THE COMMUNITY LEVEL

Fear
Fear of HIV transmission through daily contact, which may lead to discrimination, can be assessed by asking whether a person can be infected:
■ If you touch the saliva of a person with HIV or AIDS?
■ If you touch the sweat of a person with HIV or AIDS?
■ If you touch the excreta of a person with HIV or AIDS?
■ If your child plays with a child who has HIV or AIDS?
■ If you eat food prepared by a person with HIV or AIDS?

TABLE 6.1: ASSESSING STIGMA AT THE COMMUNITY LEVEL
Shame and Blame
Stigma and discrimination based on shame, blame and judgement can be assessed by asking the following questions:
Shame
■ Would you feel ashamed if you were infected with HIV?
■ Should people with HIV or AIDS be ashamed of themselves?
■ Would you be ashamed if someone in your family had HIV or AIDS?
Blame and Judgment
■ Do female prostitutes spread HIV in our community?
■ Is HIV a punishment for bad behaviour?
■ Are people with HIV or AIDS promiscuous?
■ Is HIV a punishment from God?
Discrimination
The level of discrimination can be assessed by asking people whether they are aware of or have seen incidents during which a person living with HIV or AIDS experienced:
Isolation (including physical and social exclusion)
■ Excluded from a social gathering
■ Abandoned by partner
■ Abandoned by family or sent away
Verbal stigma
■ Teased, insulted, sworn at
■ Gossiped about
Loss of identity/role
■ Lost respect/standing within the family and/or community
Loss of access to resources
■ Lost customers or a job
■ Had property taken away

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