

# Reducing **HIV** Stigma and Discrimination: a critical part of national **AIDS** programmes

A resource for national stakeholders  
in the **HIV** response



Cover photos by G. Pirozzi, L. Taylor and S. Noorani

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## EXECUTIVE SUMMARY

Despite the pervasiveness of HIV-related stigma and discrimination in national HIV epidemics and their harmful impact in terms of public health and human rights, they remain seriously *neglected issues* in most national responses to HIV.

“Since the beginning of the epidemic, stigma, discrimination, and gender inequality have been identified...as major obstacles to effective responses to HIV. Yet there has never been serious political and programmatic commitment to doing anything about them.”

– Peter Piot, Executive Director, Joint United Nations Programme on HIV/AIDS [2]

National AIDS programmes – together with key partners – can take concrete steps to address these critical obstacles and help pave the way towards universal access to prevention, treatment, care and support. The UN system, funding mechanisms and bilateral partners can support countries – through advocacy, strategic planning, technical assistance, resource mobilisation and other means – to reduce stigma and discrimination related to HIV. These efforts will not only help countries reach key targets for universal access and Millennium Development Goal 6, they will also protect and promote human rights, foster respect for people living with HIV and other affected groups, and reduce the transmission of HIV.

### How can national AIDS authorities, UNAIDS, UN Joint Teams on AIDS and other partners help reduce stigma and discrimination?

- **Build an understanding of and commitment to stigma and discrimination reduction by** using existing tools for measuring stigma and discrimination to “know your epidemic” in terms of the prevalence of stigma and discrimination and their impact on the response to HIV.
- **Provide leadership on the necessity of reducing stigma and discrimination in national AIDS responses.** Inspire leadership, understanding, and high-level commitment regarding the need to seriously expand efforts to address stigma and discrimination in national AIDS programmes.
- **Facilitate the inclusion of stigma/discrimination reduction in national HIV strategic planning, funding and programming activities.** Ensure that planning, funding and programming efforts include attention to stigma and discrimination and support the implementation of promising programmes to address stigma and discrimination.
- **Use or promote approaches that address the root causes of stigma and discrimination.** Implement programmes that tackle the actionable causes of stigma, i.e. lack of awareness of stigma and discrimination and their negative consequences; fear of acquiring HIV through casual contact; and linking HIV with behaviour that is considered immoral or improper.

■ **Advocate for a multifaceted national approach to stigma and discrimination.**

A national response which employs a range of approaches will have the greatest impact, e.g. “know your rights” campaigns; social change communication; social mobilization; participatory education; interaction between people living with HIV and key audiences; celebrity champions and media campaigns; legal support to those affected by stigma and discrimination.

■ **Facilitate the scale-up of effective programmes.** National AIDS programmes – working with partners – can identify promising approaches to stigma and discrimination that can be taken to scale to achieve sufficient impact across the country.

■ **Promote and facilitate programme evaluation and operational research.** Measurement helps evaluate effectiveness and the identification of programmes to scale up and can be built into programmes during design and implementation.

## INTRODUCTION

"...If we do not appreciate the nature and impact of stigma, none of our interventions can begin to be successful. AIDS is probably the most stigmatised disease in history."

– Edwin Cameron [7]

National AIDS programmes and the international community have embraced the goal of universal access to HIV prevention, treatment, care and support by 2010 [9]. To achieve this goal, countries will need to address the obstacles blocking provision and uptake of prevention, treatment, care and support. From the late 1980s to the commitment to universal access (2005–2006), experts and communities have consistently identified HIV-related stigma and discrimination as critical barriers to effectively addressing HIV [11]. In addition to being globally pervasive, stigma and discrimination operate at multiple levels throughout society: within individuals, families, communities, institutions and media, and in government policies and practices [12, 13]. Yet despite the recognition of the significance and prevalence of stigma and discrimination, almost no country has prioritized activities to reduce or eliminate them in their national AIDS plans or programmes. Unless this changes, universal access will not be achieved.

This document presents strategies, programme examples and research findings concerning how governments, the UN system, donors and civil society can make the reduction of HIV-related stigma and discrimination central in the national response to AIDS. Development partners – as they support national authorities and civil society partners in scaling up toward universal access – can inspire greater political, financial and programmatic commitment to address stigma and discrimination in national AIDS responses. UNAIDS and United Nations Joint Teams on AIDS can work with national authorities to ensure that national strategic plans for achieving universal access address the multiple ways that stigma and discrimination hinder HIV prevention, testing and counselling, care, support and treatment. Most importantly, Government leaders and national AIDS authorities can make the reduction of stigma and discrimination a key pillar of national AIDS strategies and programmes both to protect those affected and to reduce the transmission and impact of HIV.



## SECTION 1

### Why stigma and discrimination are major “road blocks” to universal access to HIV prevention, treatment, care and support



UNAIDS/G. Pirozzi

In many countries and communities, the stigma associated with HIV and the resulting discrimination can be as devastating as the illness itself: abandonment by spouse and/

or family, social ostracism, job and property loss, school expulsion, denial of medical services, lack of care and support, and violence. These consequences, or fear of them, mean that people are less likely to come in for HIV testing, disclose their HIV status to others, adopt HIV preventive behaviour, or access treatment, care and support. If they do, they could lose everything.

#### *Lower Uptake of HIV Preventive Services and Testing and Counselling*



UNAIDS/B. Neelaman

Globally, stigma and discrimination are associated with lower uptake of HIV preventive services, including under- or non-participation in HIV information meetings and

counselling [14] and reduced participation in programmes to prevent mother-to-child transmission [15, 16]. Stigmatising attitudes are associated with denial of risk and a lower likelihood of adopting preventive behaviours [17, 18]. Both the fear of stigma [15, 19] and stigmatising beliefs – which perpetuate the notion that HIV only happens to others – keep people from HIV testing [19] in numerous contexts.

#### *Reduced and Delayed Disclosure*

Disclosure of HIV serostatus is key for outcomes ranging from condom use to care-seeking. Numerous studies have found stigma and discrimination adversely affect disclosure to partners, health care providers and family members [3, 10, 20].

#### *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 because of fear of breaches of confi-

#### **Box 1 – Defining HIV-related stigma and discrimination**

UNAIDS defines HIV-related stigma and discrimination as: “...a ‘process of devaluation’ of people either living with or associated with HIV and AIDS...Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status.” [1] It is important to note that even if a person feels stigma towards another, s/he can decide to not act in a way that is unfair or discriminatory.

#### **Box 2 – Stigma and HIV services: selected statistics**

##### *Prevention and testing*

- In Botswana, a survey of patients receiving antiretroviral therapy found 40 per cent delayed getting tested for HIV, mostly due to stigma [3].
- In a survey of injecting drug users in Indonesia, 40 per cent said stigmatisation was why drug users avoided HIV testing [4].

##### *Disclosure*

- A study among Tanzanian persons living with HIV found only half of respondents had disclosed their status to intimate partners. Among those who disclosed, the average time from knowing to disclosure was 2.5 years for men and 4 years for women [6]. Stigma contributed to delayed disclosure.

##### *Care and Treatment*

- In a survey of more than 1,000 healthcare professionals working directly with HIV patients in four Nigerian states, 43 per cent observed others refusing a patient with HIV hospital admission [8].
- In Jamaica, researchers found that more than two-thirds of newly diagnosed AIDS cases in 2002 tested late in the progression of their illness, a phenomenon linked to stigma and homophobia. The remaining third were reported as deaths, indicating patients failed to seek care and support as their disease progressed [10].

dentiality, and nonadherence to medicines [21, 22]. Stigma may also compel people to conceal medicines, which may result in inconsistent doses [22].

### ***Stigma and Discrimination Disproportionately Affect Women and Girls***

Women tend to experience greater stigma and discrimination than men, are more likely to experience its harshest and most damaging forms, and have fewer resources for coping with it [13, 25, 29–31]. Violence is a severe consequence of stigma faced principally by women [32–34]. Both women and girls report increased violence at the hands of their partners for requesting condom use, accessing voluntary testing and counselling, refusing sex within or outside marriage or for testing HIV-positive [35–38].

### ***Magnified Effects among Socially Vulnerable Groups***



UNAIDS/C. Sartilberger

Stigma and discrimination are daily realities for people living with HIV and for people belonging to groups particularly vulnerable to HIV infection. Such groups include sex workers, men who have sex with men, people who inject drugs, prisoners and people with tuberculosis. Members of these groups are already stigmatised and are more likely to face more discrimination than others when diagnosed with HIV, including being refused services [27, 28]. The layered stigma that people in these groups experience further heightens

the challenge of meeting their needs with respect to HIV [10, 25, 26]. Members of these groups often avoid, or delay, seeking needed services for fear of being “found out”, humiliated, and/or treated differently by health workers, and, in some instances, prosecuted and imprisoned. [4, 23, 24].

## SECTION 2

### How national AIDS programmes can reduce stigma and discrimination



UNAIDS/G. Pirozzi

In recent years, researchers and practitioners have made significant progress in identifying the causes and dimensions of stigma and discrimination [13, 25, 27, 31, 39, 40], developing practical tools for programmes with multiple audiences [41-45], and standardizing measures for evaluating programmes [6]. This work has culminated in a set of general principles for tackling stigma and discrimination. These are: (a) address the causes of stigma and discrimination and the key concerns of affected populations, (b)

measure stigma as part of “knowing your epidemic and response” and implement/scale-up effective programmes, (c) use a multifaceted approach to reduce stigma and discrimination, and (d) evaluate stigma and discrimination-reduction efforts. These principles form the basis for the proposed actions that national AIDS programmes can take – together with donors and civil society – to reduce stigma and discrimination.

#### **Action 1: Use or promote approaches that address the root causes of stigma and the key concerns of affected populations**



UNAIDS/G. Pirozzi

An overarching principle for tackling stigma and discrimination is to address their immediate underlying causes, which are remarkably similar across different countries and continents [13]. While there are many causes of stigma, **Table 1** focuses on the ‘actionable’ causes that can be effectively challenged through programmes, and provides recommendations for addressing each cause. These recommendations apply to all target audiences.

National AIDS authorities, UNAIDS and United Nations Joint Teams on AIDS should ensure that key stakeholders working to address HIV – such as Government and UN officials, donors, the media, civil society, non-governmental organisations, faith-based organisations and organisations of people living with HIV – are aware of the actionable causes of stigma and discrimination. In addition, they should advocate for funds to support national programmes that address these causes and support governments to prioritise such programmes in their national strategic plans and annual action plans. They should also facilitate the participation of networks of people living with HIV, and representatives from other key affected populations, in national planning processes for designing, funding and implementing stigma and discrimination-reduction activities. This will help ensure their concerns are addressed in national responses to HIV (See **Box 3**) [5].

**Table 1 – Addressing the causes of stigma and discrimination**

Actionable Causes	What to do?	Target Audiences
1. Lack of awareness and knowledge of stigma and discrimination and their harmful effects	<p>1.1 Create awareness of what stigma and discrimination are, the harm they cause, and the benefits of reducing them, using a combination of:</p> <ul style="list-style-type: none"> <li>– Participatory education, which involves activities that encourage dialogue, interaction and critical thinking;</li> <li>– “Contact strategies”, which involve direct or indirect interaction between people living with HIV and key audiences to dispel myths about people affected by HIV; and</li> <li>– Mass media campaigns.</li> </ul> <p>1.2 Foster motivation for change through advocacy and awareness campaigns engaging:</p> <ul style="list-style-type: none"> <li>– Key opinion leaders (e.g. celebrities, political leaders, religious leaders, sports stars); and</li> <li>– People living with HIV, and members of marginalized groups.</li> </ul>	Government and other officials, media, civil society, institutions (e.g. hospitals, schools, workplace), non-governmental organisations, faith-based organisations, organisations of people living with HIV, general population.
2. Fear of acquiring HIV through everyday contact with infected people because of lack of detailed knowledge and information	<p>2.1 Address fears and misconceptions about HIV transmission by providing <b>detailed</b> information about how HIV is and <b>is not</b> transmitted using a combination of:</p> <ul style="list-style-type: none"> <li>– Behaviour change communication strategies (e.g. mass media campaigns and “edutainment”);</li> <li>– Participatory education; and</li> <li>– Free telephones hotlines/helplines.</li> </ul>	Government and other officials, media, civil society, institutions (e.g. hospitals, schools, workplace), non-governmental organisations, faith-based organisations, organisations of people living with HIV, general population.
3. Linking people with HIV with behaviour that is considered improper and immoral.	<p>3.1 Discuss the ‘taboos’ – including gender inequalities, violence, sexuality, and injecting drug use – using a combination of:</p> <ul style="list-style-type: none"> <li>– Participatory education;</li> <li>– Contact strategies (see 1.1);</li> <li>– Behavioural and social change communication; and</li> <li>– Equipping stigmatised individuals and groups to challenge stigma and discrimination and to change behaviour (see page 16).</li> </ul> <p>3.2 Mobilise action to challenge stigma and discrimination at the national and community levels through:</p> <ul style="list-style-type: none"> <li>– Advocacy and awareness campaigns;</li> <li>– Community involvement in planning for stigma and discrimination reduction;</li> <li>– Know your rights campaigns supported by legal assistance; and</li> <li>– Strategic litigation against discrimination in various settings.</li> </ul>	Government and other officials, media, civil society, institutions (e.g. hospitals, schools, workplace), non-governmental organisations, faith-based organisations, organisations of people living with HIV, general population.

*Adapted from ICRW and DFID [13, 46].*

**Action 2: Facilitate the measurement of stigma and discrimination as part of “knowing your epidemic and response”, and scale-up effective programmes in the context of national AIDS strategic plans, annual action plans, and the mobilisation of funds**

Knowing the prevalence of HIV-related stigma and discrimination and knowing their impact on the uptake of HIV prevention, testing, treatment, care and support are essential elements of “knowing your epidemic and response” and matching your response to the actual needs. Through the use of available tools by which to measure stigma and discrimination, it is possible to get a greater understanding of their prevalence and impact (See Annex B). Countries should look for opportunities (for instance, in the national monitoring and evaluation framework) to understand how stigma and discrimination impact all HIV programme efforts, and use that information to integrate stigma and discrimination-reduction activities into broader HIV prevention, care and treatment efforts.

A number of pilot programmes to reduce stigma and discrimination have demonstrated success (See Annex A). National AIDS programmes, together with key partners, should become aware of such programmes and develop, or scale-up, similar stigma and discrimination-reduction programmes in their own national AIDS responses.

UNAIDS, Joint United Nations Teams on HIV and funders should work with countries to ensure that proposals for national AIDS funding include components related to the funding of such programmes to reduce stigma and discrimination.

**Action 3: Advocate for and implement a multifaceted national approach to reduce stigma and discrimination**

Stigma, discrimination and underlying norms governing gender, sexuality, risk-taking and other factors are often enforced at the family, community, institutional, and legal and policy levels. Thus, a range of approaches, operating at multiple levels with multiple target audiences, are needed to address the causes of stigma and discrimination. Some of these approaches will work to change stigmatizing attitudes; some will work to stop discriminatory behaviour. Such a multifaceted response will have the greatest and broadest impact. National AIDS programmes – with the support of key partners – can develop and implement a multi-faceted approach by drawing upon existing programme models that have successfully employed approaches to: (a) prevent and reduce stigma, (b) challenge discrimination in law and in institutional settings, and (c) build human rights and legal capacity (See **Table 2** and **Annex A**).

**Box 3 – People Living with HIV Stigma Index**

To better understand the stigma and discrimination experienced by people living with HIV, the Global Network of People Living with HIV (GNP+) and the International Community of Women living with HIV/AIDS (ICW), with the support of the International Planned Parenthood Federation (IPPF) and the UNAIDS Secretariat, have developed the People Living with HIV Stigma Index.

The People Living with HIV Stigma Index has been designed by and for people living with HIV, using a questionnaire that focuses on different aspects of stigma and discrimination experienced by positive people including: social exclusion, access to work and health services, internal stigma, having children, knowledge and use of legal protection, effecting change, and HIV testing and disclosure.

Importantly, the Index is designed detect the prevalence of and changes in stigma over time. It can also be a useful policy, advocacy and capacity-building tool for organisations working at the community and national levels. [5].

**Table 2 – An effective national response to reduce stigma and discrimination...**

Addresses actionable causes of stigma and discrimination	Programmes need to address the actionable causes of stigma and discrimination: lack of understanding of stigma and its harms, fear of infection through casual contact, association with illegal or immoral behaviours.
Addresses multiple layers of stigma and discrimination	Vulnerable groups typically experience stigma based on multiple attributes (e.g. HIV status, sexuality, ethnicity, poverty, drug use, gender, sex work). Thus, programmes that address HIV stigma and discrimination alone may not improve prospects for these groups or improve the response to AIDS.
Operates at multiple levels	Individual; family; community; organisational/institutional; and government/legal.
Engages multiple target audiences, potential change agents, and marginalised and vulnerable populations	These include: opinion leaders (e.g., politicians, parliamentarians, judges, faith-based leaders, celebrities), front-line HIV responders (e.g. healthcare workers, legal service providers, human rights advocates, NGO and community workers), people living with HIV, affected communities, the media, private sector, schools, the police and armed services.
Employs a range of approaches to: 1. Prevent and reduce stigma 2. Challenge discrimination in law and in institutional settings 3. Build human rights and legal capacity.	Successful approaches will involve a combination of: <ul style="list-style-type: none"> <li>• Strengthening and building capacity of stigmatised individuals and groups, e.g., through skills-building, legal services, “know your rights” campaigns, network building, counselling, training, income generation</li> <li>• Social mobilization strategies for social, legal and economic support and action, in advance of, or in response to, stigmatizing speech or discriminatory practice</li> <li>• Contact or interaction with people living with HIV and other most at risk people, e.g. men who have sex with men, sex workers, injecting drug users</li> <li>• Participatory and interactive education</li> <li>• Behavioural and social change communication: e.g. media campaigns, “edu-tainment” programmes; campaigns on human rights, women’s rights, and against violence against women</li> <li>• Institutional reform, e.g. addressing discrimination in courts, workplaces, healthcare settings, schools and among police</li> <li>• Provision of training on non-discrimination to health care provider and establishment of codes of conduct and oversight for service providers</li> <li>• Legal action: law reform, provision of legal support services for those discriminated against, community legal assistants, working with traditional leaders in customary law, strategic litigation against HIV-related discrimination in employment, education, armed services, child custody, property and inheritance rights</li> <li>• Policy dialogue and reform, together with reporting, enforcement and mechanisms for redress, especially at local levels</li> </ul>

*Adapted from DFID [46]*

#### **Action 4: Promote and facilitate the monitoring and evaluation of programmes to reduce stigma and discrimination**

Assessments of progress and impact in stigma/discrimination reduction have been often neglected. While data available from pilot programmes have identified promising strategies for scale-up, more evidence on successful approaches is needed, particularly for groups experiencing multiple stigmas.

Operational research, which involves applied, action-oriented research on promising strategies, can help fill these gaps. National AIDS authorities, UNAIDS and United Nations Joint Teams on AIDS should work together to support governments and programme partners to incorporate operational research, where possible, into on-going and planned stigma and discrimination-reduction activities. In addition, they should promote the use of standardized measures to monitor and evaluate progress over time. This will enable regional and global comparison of results and help identify effective, broadly applicable strategies.<sup>1</sup>

## Key Lessons for Implementation

**The most promising approaches to stigma and discrimination-reduction feature a combination of the following strategies: empowerment of people living with HIV, updated education about HIV, and activities that foster direct or indirect interaction between people living with HIV and key audiences.** This type of interaction, whether through mass media, “meet the people” panels, or working together toward common goals, is considered particularly useful in dispelling harmful myths and changing attitudes [47]. Participatory education – which encourages people to reflect on their own attitudes and actions – is especially effective for inspiring individual change around stigma and discrimination at any level, but in particular, at the community level [13, 48].

**A participatory approach, which involves activities that encourage dialogue, interaction and critical thinking, is at the core of several promising stigma and discrimination reduction programmes** [45]. These programmes have involved interactive workshops with diverse audiences. Examples include work with Government officials in Viet Nam, teachers in Zambia, and healthcare workers in India, Viet Nam, and Tanzania [41, 43, 49–51]. The model features reflection exercises, role-plays, and discussions. These foster greater understanding of false assumptions underlying the stigma, the harm stigma and discrimination cause and the need to change attitudes and behaviours. The involvement of people living with HIV as facilitators has added to the transformative power of these activities. Action planning is an important end result. After participating in this type of workshop, leaders of the Commission for Ideology and Culture of the Communist Party in Viet Nam, which controls all media and party messaging, formulated a set of media guidelines on conducting non-stigmatizing reporting on HIV and AIDS. [43]

**One promising mechanism for scaling-up stigma reduction activities quickly and effectively is to conduct a cascade of Training of Trainers workshops.** A regional training programme, using the toolkit “Understanding and Challenging HIV Stigma: A Toolkit for Action”, has been rolled out in sub-Saharan Africa [51], and can be replicated and adapted for other settings. This programme has trained national teams of stigma trainers in ten countries, who then conduct community workshops and train community-based, faith-based and non-governmental organizations to integrate stigma and discrimination-reduction activities into their existing programmes. National AIDS programmes, UNAIDS, the United Nations Joint Teams on AIDS and other partners can draw upon the large cadre of trainers throughout Africa that have been trained by this programme.

**Reducing stigma and discrimination in health facilities requires not only addressing the attitudes and practices of health care workers but also meeting their needs for HIV**

1 See Annex B on measurement. A set of measurement indicators recently validated in Tanzania may be helpful for this purpose. These measures include questions to assess common underlying fears, such as the fear of contracting HIV through causal contact, and “values-driven stigma”, in which HIV is linked to behaviours considered improper or immoral, resulting in shame, blame and judgment. There are also a number of questions that assess common forms of discrimination, or ‘enacted stigma’, both observed and experienced. These measures can be used to gauge the success of efforts to reduce stigma and discrimination over time.

**information, training in health care for people living with HIV, and supplies for universal precautions to prevent occupational exposure to HIV.** Programmes in healthcare facilities have successfully improved services for people living with HIV, and resulted in a safer working environment for health workers. Research suggests that policies and programmes must be directed at *all* hospital employees – from the cleaning staff to hospital superintendents – since everyone has a role to play in changing attitudes and behaviours. With tools such as the “PLHA friendly” Checklist, healthcare managers can review facility-specific information on stigma and devise their own solutions. Using these and similar approaches, stigma and discrimination-reduction is manager-led, participatory, and more effective [44].

**Programmes promoting a combination of social mobilization, human rights and legal activism turn “victims” of stigma and discrimination into empowered groups engaged in self-determination and social change** [52, 53]. A number of programmes operating at the policy and legal levels have made treatment more widely available, and addressed the stigma and discrimination experienced by people living with HIV and other vulnerable groups. Groups of people living with HIV have successfully worked with lawyers’ organisations to use the law to advance legal protections, e.g. the Lawyers’ Collective in India and the AIDS Law Project in South Africa, both of which have defended the rights of people living with HIV against discrimination.<sup>2</sup> South Africa’s Treatment Action Campaign, where members announce they are “HIV positive” and assert their rights to prevention and treatment, is an empowerment approach involving a combination of social mobilisation, “know your rights” and treatment literacy campaigns, and strategic litigation [54]. With multiple court victories and demonstrable success in expanding access to treatment, the Treatment Action Campaign is a successful rights-based model. Key elements of the approach are the leadership and active engagement of people living with HIV in advocacy, education, litigation and other activities [28].

**People living with HIV need to be actively involved in developing and implementing stigma and discrimination-reduction efforts** [52, 53]. Transformative approaches that empower affected persons to become “change agents” and act collectively to challenge discrimination are recommended by numerous researchers [12, 54, 55]. Speaking out to challenge discrimination, however, is difficult and sometimes even dangerous. It may be necessary to address internalised stigma and foster community support before employing these approaches. Leader-to-leader advocacy and public displays of solidarity can open space for dialogue and reduce fear. This will help enable public disclosure of sero-status and advocacy efforts. People living with HIV may need new skills and ongoing support to take active, visible roles in anti-stigma efforts. Additionally, ensuring their health needs are met, particularly for treatment, is critical for sustained engagement in these efforts. Thus, the reduction of stigma and discrimination is another reason why governments, UNAIDS, the Joint United Nations Team on HIV and funders should support major programmes in national AIDS responses for capacity-building of groups of people living with HIV and other vulnerable populations.

**An effective scaled-up national response will employ a range of approaches to: (a) prevent and reduce stigma and discrimination among different key audiences and communities; (b) challenge stigma and discrimination in institutional settings; and (c) build human rights and legal capacity.** Annex A presents an overview of successful programmes that have tackled these issues. As national AIDS programmers, UNAIDS, the Joint United Nations Team on AIDS and other stakeholders work together to develop a roadmap of activities for reducing stigma and discrimination, they can refer to these programmes and key lessons learned to facilitate planning, support and implementation.

2 For examples of specific cases, see UNAIDS and Canadian HIV/AIDS Legal Network (2005), *Courting Rights: Case Studies in Litigating the Human Rights of People Living with HIV*. Geneva: Joint United Nations Programme on HIV/AIDS. Available on-line: [http://data.unaids.org/Publications/IRC-pub07/JC1189-CourtingRights\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/JC1189-CourtingRights_en.pdf)

## SECTION 3

### Steps toward effective responses to HIV stigma and discrimination



UNAIDS/G. Pirozzi

There are a number of steps that national AIDS programmes, UNAIDS and Joint United Nations Teams on AIDS, working in collaboration with key partners, can take to facilitate country-wide stigma and discrimination reduction. These actions and specific recommendations are summarized in **Table 3**, and include: (a) building an understanding of and commitment to stigma/discrimination reduction, (b) providing leadership on the necessity of

reducing stigma and discrimination in national AIDS responses, and (c) facilitating the inclusion of stigma/discrimination in the national HIV strategic planning, funding and programming efforts.

The first key step is to **build an understanding of and commitment to stigma/discrimination reduction**. Whether coming to the HIV response as the national AIDS programme, UNAIDS, the UN Country Team, a civil society group or a member of the donor community, a solid understanding of stigma and discrimination is important for effective advocacy and for directing support to programmes. Starting “at home” to raise awareness among staff members, and address any stigmatising attitudes and discriminatory practices that may exist within the organisation not only reduces “home-based” stigma but also leads to a stronger understanding of the general issue of HIV stigma and discrimination and a greater commitment to doing something about them in the national response to HIV. These activities should be combined with efforts to measure the prevalence of stigma and discrimination in the country and within key communities as a part of “knowing your epidemic and response” and matching your response to the current needs, as described earlier. Such knowledge provides the basis from which to support and include stigma and discrimination programmes in national HIV responses.

The second step is to **provide leadership on the necessity of reducing stigma and discrimination in national AIDS responses**. As mentioned, stigma and discrimination have been neglected in national responses to HIV, partly out of lack of awareness of how harmful these are to effective responses to HIV and partly out of lack of experience regarding how to address them. Also many stakeholders, including governments and donors, have perceived stigma and discrimination as “too culturally specific” and complicated to address, being unaware of research which indicates that there are common features everywhere and these can be addressed effectively [13]. In light of these continuing perceptions, there is need for sustained leadership on the multiple harms of stigma and discrimination and the importance of reducing them in order to achieve an effective response. Such leadership is crucial to unblock the lack of commitment to funding and programming around stigma and discrimination.

The third step is to **facilitate the inclusion of stigma/discrimination in national HIV strategic planning, funding and programming efforts**. There is need to undertake efforts to analyse (a) what programmes to reduce stigma and discrimination can be included in national strategic plans and annual action plans, (b) where existing activities can be scaled-up, and (c) where new activities need to be developed and incorporated to achieve appropriate national coverage. UNAIDS and the UN Joint Team on AIDS can play important roles in supporting key stakeholders, such as Government ministries and institutions, country coordinating mechanisms, national human rights institutions, international and local non-governmental organisations and private sector companies, to take on and have input into programming and funding stigma and discrimination-reduction activities in national AIDS responses.

**Table 3 – A Strategy for Programmatic Action to Reduce Stigma & Discrimination**

Action	Proposed Steps	Illustrative Benchmarks
Build an understanding of and commitment to stigma and discrimination reduction	<ul style="list-style-type: none"> <li>• Raise awareness among colleagues on HIV stigma and discrimination, their adverse effects on national responses to HIV, and how to address them. (See “Living in a World with HIV”, a resource for UN employees and their families: <a href="http://unworkplace.unaids.org/UNAIDS/common/docs/UNAIDSengALL-Jan24.pdf">http://unworkplace.unaids.org/UNAIDS/common/docs/UNAIDSengALL-Jan24.pdf</a>).</li> <li>• Organise stigma/discrimination reduction workshops in your offices and promote awareness of the ILO workplace policy on HIV and AIDS. The most effective workshops include people living with HIV. (See “An ILO code of practice on HIV/AIDS and the world of work”, on-line at <a href="http://www.ilo.org/public/english/protection/trav/aids/code/languages/hiv_a4_e.pdf">http://www.ilo.org/public/english/protection/trav/aids/code/languages/hiv_a4_e.pdf</a>).</li> <li>• Support the establishment of an association of employees living with HIV. For an example from the UN system, see the web site of UN+, the UN System HIV Positive Staff Group (<a href="http://www.unplus.org/">http://www.unplus.org/</a>).</li> <li>• Use tools to measure stigma and discrimination in the country, such as the PLHIV Stigma Index, to “know your epidemic and response” in terms of the harmful impact that stigma and discrimination are having on the HIV response and the need to address them in the national response.</li> </ul>	<ul style="list-style-type: none"> <li>• Root causes of stigma discussed and agreed by National AIDS Coordinating Authority</li> <li>• Number of stigma reduction workshops held in various Government offices</li> <li>• Stigma and discrimination incorporated into policies, programmes and analysis</li> </ul>
Provide leadership on the necessity of reducing stigma and discrimination in national AIDS responses	<ul style="list-style-type: none"> <li>• In dialogue with leaders in the public, private and not-for-profit sectors, raise awareness and inspire greater action on stigma and discrimination.</li> <li>• Convey the sense that change is possible. Practical and proven tools exist and examples of successful programmes are available (See <b>Annex A &amp; C</b>).</li> <li>• Foster ‘advocates for change’ among national and UN leadership who can spearhead efforts at other levels (e.g. provincial and district level government, UN Resident Coordinator, parliamentarians, judges, community-based organisations, faith-based organisations, private sector).</li> <li>• Intensify government programming against stigma and discrimination. Engage a range of Ministries, including Health, Justice, Interior, Defence and Education in discussions. Additionally, national human rights institutions, law reform commissions and parliamentary committees have important roles to play.</li> <li>• Promote laws supporting the rights of people living with HIV and legal measures against domestic violence, which can be a consequence of HIV stigma. Enforcement of existing laws is also critical.</li> <li>• Support free telephone helpline services to enable concerned people to seek information and report discrimination.</li> <li>• Ensure staff members have tools for effective advocacy and action, e.g. evidence-based advocacy points (See <b>Annex D</b>), resources providing deeper background on stigma and discrimination [46], and examples of successful programmes (see <b>Annex A</b>).</li> </ul>	<ul style="list-style-type: none"> <li>• All relevant government ministries sensitized</li> <li>• Foster at least one advocate in each ministry</li> <li>• All HIV-related policies have been updated with non-stigmatising language</li> <li>• Institutional HIV-related policies are in line with national policies</li> </ul>

Action	Proposed Steps	Illustrative Benchmarks
<p>Facilitate the inclusion of stigma/discrimination reduction in national HIV strategic planning, funding and programming efforts</p>	<ul style="list-style-type: none"> <li>• Raise the priority of stigma/discrimination reduction by promoting its inclusion in national AIDS plans and country roadmaps towards universal access.</li> <li>• Promote meaningful participation of people living with HIV, as well as legal, human rights and other groups, in planning and policymaking processes related to stigma/discrimination reduction.</li> <li>• Facilitate a rapid, national assessment of programming and policy efforts across sectors and implementing partners to answer the following questions: <ul style="list-style-type: none"> <li>– Are laws and policies in place?</li> <li>– Are workplace programmes in place to train key service providers in non-discrimination (e.g. health care workers, social assistance officers, police)?</li> <li>– Which organisations are already working on stigma and discrimination?</li> <li>– What are the existing projects to reduce stigma and discrimination that might be supported, scaled-up and integrated into the National AIDS Action Framework?</li> </ul> </li> <li>• Support the development of a comprehensive strategy for scaling-up activities, and integrating them into the National AIDS Action Framework.</li> <li>• Promote stigma/discrimination reduction efforts not only in health, but in education, justice, armed services and other areas. Where possible, ensure a coordinated approach across programme areas to enhance synergies (e.g. supporting networks of people living with HIV and the enforcement of laws protecting the rights of people living with HIV).</li> <li>• Organize a Stigma and Discrimination Reference Group, including representatives from the National AIDS Coordinating Authority, the United Nations Joint Team on AIDS, organisations of people living with HIV, legal and human rights groups, the National Human Rights Institution, and other key partners, to: <ul style="list-style-type: none"> <li>– Facilitate the development of country-specific stigma/discrimination-reduction programmes.</li> <li>– Facilitate the review of programmatic and evaluation data to assess progress towards reducing stigma and discrimination and the impact of reduction on universal access to prevention, treatment, care and support.</li> <li>– Ensure that institutions and organisations have adequate skills and tools to monitor and evaluate stigma/discrimination reduction activities (e.g. training on using key stigma-reduction toolkits, support to incorporate standardized and validated measures to assess stigma and discrimination in programme evaluation surveys, etc.)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Report summarizing findings from national assessment</li> <li>• Report outlining national strategy for scaling-up stigma-reduction activities</li> <li>• Number of workshops held on measuring stigma and discrimination</li> <li>• Key stigma-related evaluation findings included in progress report on national M&amp;E framework</li> <li>• National meeting to review evaluation findings and re-visit/update National AIDS Action Framework</li> </ul>

Action	Proposed Steps	Illustrative Benchmarks
	<ul style="list-style-type: none"> <li>- Facilitate the incorporation of stigma/discrimination indicators into the National Monitoring and Evaluation Framework and ensure that mechanisms are in place so programme data can be reported and reviewed efficiently.</li> <li>- Ensure that findings are utilized in reviewing and updating the National AIDS Action Framework.</li> <li>• Assist implementing partners in costing and preparing budgets for stigma/discrimination-reduction activities integrated within the National AIDS Action Framework.</li> <li>• Mobilise domestic and international resources to ensure appropriate funding for country-specific stigma/discrimination-reduction activities (e.g. advocate with Treasury/Ministry of Finance and donors on importance of reducing stigma and discrimination in context of moving towards universal access).</li> <li>• Facilitate the incorporation of stigma/discrimination-reduction activities into funding proposals (e.g. support workshops on proposal-writing for stigma/discrimination-reduction and/or provide guidelines/suggestions for incorporating stigma/discrimination-reduction into proposals).</li> <li>• Facilitate international technical support, and cultivate domestic technical support, to assist implementing partners in designing, implementing and evaluating stigma/discrimination-reduction programmes.</li> </ul>	<ul style="list-style-type: none"> <li>• Amount of money allocated to fund stigma and discrimination-reduction activities (domestic resources, Global Fund, World Bank, other bi-lateral and multi-lateral sources)</li> <li>• Number of proposals including a stigma-reduction component submitted</li> <li>• Number of proposals including a stigma-reduction component funded</li> </ul>

## CONCLUSION

For years, experts, researchers and people living with HIV have identified stigma and discrimination as major drivers of the HIV epidemic. In 1987, Jonathan Mann, then director of the World Health Organization's Global Programme on AIDS, forecast three components to the HIV epidemic: the first would be HIV, the second AIDS, and the third would be stigma, discrimination, and denial. He predicted that stigma, discrimination, and denial would be as central as the illness itself [27, 56]. It is tragic that twenty years later, stigma and discrimination would continue to be major problems, even in an era where treatment for HIV is more and more accessible, and prevention of HIV is not only more and more possible, it is critical.

As national AIDS programmes and the international community mount an ambitious effort to make universal access to HIV prevention, treatment, care and support a reality, all stakeholders in the AIDS response must work together to address major obstacles to reaching this goal. Greater leadership is needed to raise awareness and spur concrete action to address the obstacle of HIV stigma and discrimination, building on what has been learned through programmatic experience to date. Donors, UNAIDS and United Nations Joint Teams on AIDS can work together to support countries to include programmes to reduce stigma and discrimination as a central part of effective national responses to HIV. Not only will these efforts help countries achieve critical HIV programme and Millenium Development Goal targets, they will also help to protect the human rights of people living with HIV and other affected groups, will enable people to utilise information and services to reduce the transmission of HIV, and will reduce the impact of HIV on individuals, communities and organisations.

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## ANNEX A

### Reducing HIV Stigma and Discrimination: Successful Programmes

Programme (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	Target Audience	Key Activities by Objective <sup>4</sup>	Outcomes
<p><b>Belarus</b> <i>Involvement of People Living with HIV and Their Families in HIV-Prevention Activities</i> (integrated programme)</p> <p>Positive Movement 3, Ulyanovskaya Str. Minsk 220030, Belarus (375) 17 227 18 36 <a href="mailto:positive_movement@tut.by">positive_movement@tut.by</a></p> <p>UNDP Belarus <a href="http://un.by/en/undp/db/bye-01-005.html">http://un.by/en/undp/db/bye-01-005.html</a></p>	People living with HIV	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>• Provided people living with HIV with psychological support and legal advice to tackle internalised stigma (feelings of worthlessness, shame, and depression associated with an HIV diagnosis) and engage in advocacy</li> <li>• Implemented rights-based campaign with the media and government to raise awareness on HIV stigma</li> </ul>	<ul style="list-style-type: none"> <li>• Increased numbers of people living with HIV who willingly disclosed their status</li> <li>• Participants felt more empowered to express their needs publicly and formally to Government officials</li> <li>• A small grants fund was established to support advocacy activities in the Newly Independent States</li> </ul>
<p><b>Brazil</b> <i>Addressing the HIV Prevention, Testing, and Treatment Needs of Mobile Populations</i> (integrated programme)</p> <p>Horizons Program (Population Council) <a href="http://www.popcouncil.org/horizons">http://www.popcouncil.org/horizons</a></p> <p>Municipal Secretariat of Health, Foz do Iguaçó</p> <p>Chinaglia, Magda et al. "Reaching truckers in Brazil with non-stigmatizing and effective HIV/STI services," <i>Horizons Final Report</i>. Washington, DC: Population Council. 2007 <a href="http://www.popcouncil.org/pdfs/horizons/BrazilTruckersReport.pdf">http://www.popcouncil.org/pdfs/horizons/BrazilTruckersReport.pdf</a></p>	Long-distance truck causes	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>• Provided comprehensive health services, including voluntary counselling and testing, sexually transmitted infection management and general preventive health services, along the border at customs' areas to reduce the stigma associated with seeking HIV-related services and increase uptake</li> </ul>	<ul style="list-style-type: none"> <li>• HIV testing increased over the 18-month research period</li> <li>• Thousands of truckers were reached with comprehensive health services</li> <li>• Surveyed truckers rated the services as "great" or "good," noting their satisfaction was due to the provision of health services for not only HIV and sexually transmitted infections, but also for common illnesses</li> </ul>

3 **Integrated programmes** are those which include a stigma and discrimination-reduction component in a "traditional" HIV programme. **Stand-alone programs** are those in which all activities are focused on stigma and discrimination-reduction.

4 It is recommended that programmes to reduce stigma and discrimination address one or more of the following objectives: a) prevent and reduce stigma among different key audiences/ communities; b) challenge discrimination in institutional settings; c) build human rights and legal capacity.

<p><b>Programme</b> (Location, Title, Type of Program<sup>3</sup>, Implementing Agency, References)</p>	<p><b>Target Audience</b></p>	<p><b>Key Activities by Objective<sup>4</sup></b></p>	<p><b>Outcomes</b></p>
<p><b>Brazil</b> <i>AIDS Care Programme</i> (integrated programme)</p> <p>Volkswagen do Brasil Via Anchieta Km 23,5 – Ala 7 CEP:09823-990 Sao Bernardo do Campo/Sao Paulo Brazil +55 11 753 4843 <a href="mailto:sbc.mmoreira@vwmail.de">sbc.mmoreira@vwmail.de</a></p> <p><i>The Business Response to HIV/AIDS: Impact and Lessons Learned.</i> Joint United Nations Programme on HIV/AIDS, Prince of Wales Business Leaders Forum, and Global Business Council on HIV&amp;AIDS, Geneva and London, 2000. 51.</p> <p><a href="http://data.unaids.org/Publications/IRC-pub05/JC445-BusinessResp_en.pdf">http://data.unaids.org/Publications/IRC-pub05/JC445-BusinessResp_en.pdf</a></p>	<p>Business sector, specifically employees of <i>VW do Brasil</i></p>	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>• Provided information, education and counseling to employees living with HIV</li> <li>• Provided treatment and care to employees living with HIV</li> </ul> <p><b>To challenge discrimination in institutional settings</b></p> <ul style="list-style-type: none"> <li>• Emphasised an institutional, anti-discrimination policy which respects confidentiality of employees and prohibits mandatory testing</li> </ul>	<ul style="list-style-type: none"> <li>• Reduction in the number of hospitalizations and costs relating to treatment and care</li> <li>• Increased level of perceived employee satisfaction</li> <li>• Improvement in the quality of life of employees</li> <li>• Reduction in the number of absences due to HIV-related illnesses</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>Caribbean</b>  <i>Champions for Change</i>                      (stand-alone programme)</p> <p>CARICOM  <a href="http://www.caricom.org/">http://www.caricom.org/</a></p> <p>PANCAP  <a href="http://www.pancap.org/">http://www.pancap.org/</a></p> <p><i>Report from the Champions for Change Conference: Reducing HIV/AIDS Stigma and Discrimination in the Caribbean. 2005, CARICOM/ PANCAP: Georgetown, Guyana.</i></p> <p><a href="http://www.pancap.org/doc.php?id=128">http://www.pancap.org/doc.php?id=128</a></p>	<p>People living with HIV, faith-based leaders, political leaders</p>	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>• Engaged celebrities, political leaders, sports stars and other influential people in advancing and modelling non-stigmatising attitudes and behaviours</li> <li>• Engaged traditional and faith-based leaders to reconsider and reform customs and attitudes that foster stigmatising attitudes and behaviours</li> <li>• Promoted indirect and direct interaction between people living with HIV and key audiences to dispel myths about people affected by HIV</li> <li>• Addressed homophobia, sexual violence, attitudes about drug users, and other underlying factors contributing to stigma and discrimination</li> </ul>	<ul style="list-style-type: none"> <li>• Separate media outlets produced HIV programming which discusses discrimination experienced by people living with HIV</li> <li>• Established a database of stigma-reduction advocates in faith-based organisations which created local programs that address stigma in home-based care initiatives</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>China (Sichuan and Yunnan Provinces)</b>  <i>China-UK HIV and AIDS Prevention and Care project</i>                      (integrated programme)</p> <p>Chinese partners at national and provincial levels with DFID</p> <p>Family Health International  <a href="http://www.fhi.org">http://www.fhi.org</a></p> <p>Futures Group  <a href="http://www.futuresgroup.com">http://www.futuresgroup.com</a></p> <p>DFID. Taking Action Against Stigma, Forthcoming, 2007.</p>	<p>Government officials, people who inject drugs</p>	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>Addressed homophobia, sexual violence, attitudes about drug users and other underlying factors contributing to stigma and discrimination</li> </ul> <p><b>To challenge discrimination in institutional settings</b></p> <ul style="list-style-type: none"> <li>Used study tours, pilot projects and advocacy to challenge political objections to harm reduction programmes (e.g. drug substitution, needle exchange) and to reduce punitive responses to drug use, men who have sex with men and sex work</li> </ul>	<ul style="list-style-type: none"> <li>The Ministry of Public Security embraced DFID's harm reduction approach with injection drug users</li> <li>DFID plans to scale up its interventions with injecting drug users and sex workers under the DFID-Global Fund China HIV and AIDS Programme (2006-2011)</li> </ul>
<p><b>Haiti</b>  <i>HIV Equity Initiative</i>                      (integrated programme)</p> <p>Partners in Health  <a href="http://www.pih.org/home.html">http://www.pih.org/home.html</a></p> <p>Zanmi Lasante  <a href="http://www.pih.org/where/Haiti/Haiti.html">http://www.pih.org/where/Haiti/Haiti.html</a></p> <p>Farmer, P. et al. (2001) Community-based approaches to HIV treatment in resource-poor settings. <i>Lancet</i>, 358: 404-409.</p>	<p>People living with HIV</p>	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>Provided essential medicines and treatment to people living with HIV based on "four pillars" (combined AIDS prevention and treatment with programs to provide comprehensive primary care; advanced tuberculosis care; improved screening and treatment of sexually transmitted infections; and emphasised women's health), which helped reduce the fear associated with an HIV diagnosis.</li> </ul>	<ul style="list-style-type: none"> <li>A model for community-based treatment in low resource settings</li> <li>Newly established antiretroviral community clinics have renewed faith in health care services among patients and providers</li> <li>The comprehensive provision of care and treatment decreased the association of an HIV diagnosis with a slow, painful death and led to increased demand for HIV testing</li> <li>TB incidence and HIV-related hospitalizations has decreased</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>India</b>  <i>Reducing HIV/AIDS Stigma, Discrimination and Gender-based Violence among Health Care Providers in Andhra Pradesh</i></p> <p>International Center for Research on Women (ICRW)  <a href="http://www.icrw.org">http://www.icrw.org</a></p> <p>Bhoruka Public Welfare Trust  <a href="http://www.bpwt.org/">http://www.bpwt.org/</a></p> <p>Duvvury, Nata and Nandini Prasad. <i>Information Bulletin: Reducing HIV/AIDS Stigma, Discrimination and Gender-based Violence among Health Care Providers in Andhra Pradesh, India</i>. August 2006. Washington, DC: ICRW.  <a href="http://www.icrw.org/docs/2006_ib-reducingviolenceandstigma.pdf">http://www.icrw.org/docs/2006_ib-reducingviolenceandstigma.pdf</a></p>	Health care providers	<p><b>To challenge discrimination in institutional settings</b></p> <ul style="list-style-type: none"> <li>• Conducted training of trainers on HIV stigma and discrimination and focused discussions specifically on methods that could engage different categories of health care providers</li> <li>• Organised and implemented material-development workshops with registered medical practitioners, traditional birth attendants and Government health workers to create new modules for existing stigma and violence-reduction toolkit</li> <li>• Trained health care providers with the adapted stigma-reduction toolkit to increase their knowledge of HIV and build their capacity to pro-actively challenge stigma and gender-based violence in their communities.</li> </ul>	<ul style="list-style-type: none"> <li>• Increased HIV knowledge among health care providers</li> <li>• Increased use of universal precautions for the prevention of transmission of HIV and other blood-borne illnesses</li> <li>• Decrease in stigmatising attitudes towards patients with HIV and AIDS</li> <li>• Decreased tolerance of gender-based violence</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>India</b>  <i>Reducing Stigma and Discrimination in Hospitals</i>            (stand-alone programme)</p> <p>SHARAN  <a href="http://www.sharan.net/">http://www.sharan.net/</a></p> <p>Horizons Program            (Population Council)  <a href="http://www.popcouncil.org/horizons">http://www.popcouncil.org/horizons</a></p> <p>Mahendra, Vaishali Sharma et al.  <i>"Reducing AIDS-related stigma and discrimination in Indian hospitals,"</i>  <i>Horizons Final Report</i>. New Delhi:            Population Council. 2006.  <a href="http://www.popcouncil.org/pdfs/horizons/inplhafriendly.pdf">http://www.popcouncil.org/pdfs/horizons/inplhafriendly.pdf</a></p>	Health care providers, hospital staff	<p><b>To challenge discrimination in institutional settings</b></p> <ul style="list-style-type: none"> <li>• Improved care and services through participatory, self-guided assessment activities with health care managers and providers</li> <li>• Initiated discussions among hospital managers and staff about the service received by people living with HIV and ways to identify and challenge stigma and discrimination faced by patients</li> </ul>	<ul style="list-style-type: none"> <li>• Facility-specific data and a "PLHA-friendly" checklist convinced managers of existing problems and allowed hospitals to devise their own stigma-reduction approaches</li> <li>• Doubled the number of health care workers categorized as having the least stigmatising attitudes</li> <li>• Improved knowledge of HIV transmission among health care workers</li> <li>• Improved knowledge of universal precautions among health care workers</li> </ul>
<p><b>India</b>  <i>Lawyers Collective HIV/AIDS Unit</i>            (stand-alone programme)</p> <p><a href="http://www.lawyerscollective.org/">http://www.lawyerscollective.org/</a>  <a href="http://www.lawyerscollective.org/%5Ehiv/current_cases/sankalp.asp">http://www.lawyerscollective.org/%5Ehiv/current_cases/sankalp.asp</a></p>	People living with HIV	<p><b>To promote and protect human rights</b></p> <ul style="list-style-type: none"> <li>• Provided public interest litigation, defended and advocated for the rights of people living with HIV</li> <li>• Conducted public awareness campaigns on HIV stigma</li> <li>• Petitioned government to provide equitable antiretroviral therapy to people with HIV</li> </ul>	<ul style="list-style-type: none"> <li>• Won several cases for workers who experienced discrimination and lost their jobs</li> <li>• Successfully upheld the "suppression of identity" clause, allowing people living with HIV to file their case under a pseudonym</li> <li>• Government established 250 antiretroviral treatment centres to provide treatment to 300,000 patients under the National AIDS Control Programme</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>India</b>  <i>Stigma and Violence Reduction Intervention</i>                      (stand-alone programme)</p> <p>International Center for Research on Women (ICRW)  <a href="http://www.icrw.org">http://www.icrw.org</a></p> <p>Bhoruka Public Welfare Trust  <a href="http://www.bpwt.org/">http://www.bpwt.org/</a></p> <p>PREPARE, India                      Duvvury, Nata et al. <i>HIV and AIDS: Stigma and Violence Intervention Manual</i>. 2006. Washington, DC: ICRW.  <a href="http://www.icrw.org/docs/2006_SVRI-Manual.pdf">http://www.icrw.org/docs/2006_SVRI-Manual.pdf</a></p>	<p>Mobile populations (female sex workers, truckers, trucker's helpers and trucker's wives)</p>	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>Utilizing participatory research methods, or "community-led action research," key populations and the community at large worked together to research, design and implement a stigma-reduction program, which sought to increase condom use between intimate partners, decrease stigmatisation toward people living with HIV, and decrease tolerance of intimate partner violence</li> </ul>	<ul style="list-style-type: none"> <li>Brought diverse groups together and enabled them to establish links between HIV and AIDS, stigma and gender-based violence, and articulate the need to address them in their communities</li> <li>Created an enabling environment which led to the acceptance of people living with HIV and their active participation in the transformatory workshops and other project activities</li> <li>Helped men understand and accept the need for change in patriarchal values systems that condone violent behaviours and violence against women</li> </ul>
<p><b>Namibia</b>  <i>AIDS Law Unit</i>                      (integrated programme)</p> <p>Legal Assistance Centre  <a href="http://www.lac.org.na/">http://www.lac.org.na/</a></p> <p>Family Health International  <a href="http://www.fhi.org/en/HIVAIDS/country/Namibia/res_namibiaworkplaceprograms.htm">http://www.fhi.org/en/HIVAIDS/country/Namibia/res_namibiaworkplaceprograms.htm</a></p>	<p>People living with HIV or affected by HIV</p>	<p><b>To build human rights and legal capacity</b></p> <ul style="list-style-type: none"> <li>Provided free legal assistance to people living with HIV and their families</li> <li>Conducted research on policy/legal responses to existing and emerging discrimination issues</li> </ul>	<ul style="list-style-type: none"> <li>Developed AIDS workplace policies for several public and private sector businesses</li> <li>Successfully lobbied the legislature for legal reforms to address HIV stigma and discrimination</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>Namibia</b>  <i>Catholic AIDS Action</i>                      (integrated programme)  <a href="http://www.caa.org.na/">http://www.caa.org.na/</a></p> <p>Byamugisha, G., Steinitz, L.Y., Williams, G., &amp; Zondi, P. (2002). Journeys of faith: Church-based responses to HIV and AIDS in three southern African countries. Strategies for Hope no. 16. St Alban: TALC</p> <p>Parker, Warren and Karen Birdsall. (2005). HIV/AIDS, Stigma and Faith-Based Organisations: A Review. DFID/Futures Group MSP.  <a href="http://www.cadre.org.za/pdf/CADRE-Stigma-FBO.pdf">http://www.cadre.org.za/pdf/CADRE-Stigma-FBO.pdf</a></p>	<p>People living with HIV, Church leaders, Youth leaders, Health care workers</p>	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>• Engaged traditional and faith-based leaders to reconsider and reform customs and attitudes that fostered stigmatising attitudes and behaviours</li> <li>• Provided HIV prevention training, home-based care, treatment and support for people living with HIV</li> <li>• Trained community leaders on community mobilisation, home-based care and HIV counselling</li> <li>• Conducted peer-education training programmes for behavioural change</li> </ul> <p><b>To challenge discrimination in institutional settings</b></p> <ul style="list-style-type: none"> <li>• Conducted training sessions for church leaders on HIV stigma reduction</li> </ul>	<ul style="list-style-type: none"> <li>• Church leaders now promote and run community health programs and actively visit people living with HIV</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>South Africa</b>                      AIDS Law Project                      (integrated programme)  <a href="http://www.alp.org.za/">http://www.alp.org.za/</a>                      Works in partnership with Canadian HIV/AIDS Legal Network  <a href="http://www.aidslaw.ca/">http://www.aidslaw.ca/</a>                      AIDS Law Project. <i>HIV/AIDS, Current Law and Policy: Women, HIV and AIDS</i>. Johannesburg: University of Witwatersrand. 2005.  <a href="http://alp.org.za.dedi20a.your-server.co.za/images/upload/WomenNov05(web).pdf">http://alp.org.za.dedi20a.your-server.co.za/images/upload/WomenNov05(web).pdf</a></p>	<p>People living with HIV, women, legal service providers, civil society organizations</p>	<p><b>To build human rights and legal capacity</b></p> <ul style="list-style-type: none"> <li>• Conducted research on social, legal, and human rights issues associated with HIV, including gender-based violence, in order to develop law, policy, and best practice recommendations</li> <li>• Built capacity of legal service providers to challenge the discrimination faced by their clientele</li> </ul>	<ul style="list-style-type: none"> <li>• Over 70,000 publications on human rights for people living with HIV were distributed to the media in 2005</li> <li>• In 2005, close to 200 training seminars were presented to community-based organisations, government officials, and international agencies</li> <li>• In partnership with the Treatment Action Campaign, the AIDS Law Project advocated with the government to publish the <i>Operational Plan on Comprehensive HIV and AIDS Care, Management and Treatment for South Africa</i> in 2003</li> <li>• Produced a guide on laws and policies that affect women's rights and how women living with HIV can respond when their rights are challenged</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<b>South Africa</b> <i>Soul City</i> (stand-alone programme) <a href="http://www.soulcity.org.za">http://www.soulcity.org.za</a>	Media, people living with HIV	<div style="background-color: #e1f5fe; padding: 2px;"> <b>To prevent and reduce stigma among different key audiences/ communities</b> </div> <ul style="list-style-type: none"> <li>• Engaged journalists and other communication professionals to steer away from sensationalized, fear-inducing coverage that perpetuated negative stereotypes and produce more accurate, positive portrayals of people living with HIV</li> </ul>	<ul style="list-style-type: none"> <li>• Five television series have been produced, reaching 16.2 million people</li> <li>• As a result of exposure to television and radio broadcasts, national attitudes toward people living with HIV have improved, particularly among youth</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>South Africa</b>  <i>Treatment Action Campaign</i>                      (integrated programme)  <a href="http://www.tac.org.za">http://www.tac.org.za</a>                      Boulle, J., and T. Avafia.                      TAC Evaluation. June 2005.  <a href="http://www.tac.org.za/Documents/FinalTACEvaluation-AfaviaAndBoulle-20050701.pdf">http://www.tac.org.za/Documents/FinalTACEvaluation-AfaviaAndBoulle-20050701.pdf</a></p>	Government officials, people living with HIV	<b>To prevent and reduce stigma among different key audiences/ communities</b>	<ul style="list-style-type: none"> <li>• Helped to de-stigmatise HIV and sexual orientation</li> <li>• Supported the right to treatment for people living with HIV by securing lower prices for antiretroviral and other essential medicines and increasing government commitment to provide prevention of mother-to-child transmission programmes</li> <li>• Redefined the relationship between medical practitioners and patients to one of partnership</li> </ul>
		<ul style="list-style-type: none"> <li>• Promoted interaction between people living with HIV and key audiences to dispel myths about people affected by HIV</li> <li>• Addressed homophobia, sexual violence, attitudes about drug users and other underlying factors contributing to stigma and discrimination</li> <li>• Provided people living with HIV with support and resources to tackle internalised stigma and engage in advocacy</li> <li>• Provided people living with HIV and other vulnerable groups with training, capacity-building and social mobilization skills around knowing and asserting their rights</li> </ul>	
		<b>To build human rights and legal capacity</b>	
<ul style="list-style-type: none"> <li>• Engaged Parliaments, the Judiciary and Ministries of Armed Services/Defense, Interior, Justice to audit and reform laws, policies and enforcement practices that made it more difficult to access HIV prevention, treatment, care and support services</li> <li>• Promoted partnerships between lawyers' groups and organizations and networks of people living with HIV to more effectively advance and enforce rights</li> </ul>			

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>Sub-Saharan Africa</b>  <i>HIV/AIDS Prevention and Impact Mitigation on the World of Work in Sub Sahara Africa</i>                      (stand-alone programme)</p> <p>International Labour Organization  <a href="http://www.ilo.org/public/english/dialogue/ifpdial/tech/hiv aids.htm">http://www.ilo.org/public/english/dialogue/ifpdial/tech/hiv aids.htm</a></p>	Judicial officials	<p><b>To build human rights and legal capacity</b></p> <ul style="list-style-type: none"> <li>• Provided training to labour courts, judges and labour inspectors to apply national labour laws and international labour standards to cases concerning HIV stigma and discrimination in the workplace</li> </ul>	<ul style="list-style-type: none"> <li>• Demand for training is continuous</li> <li>• Labour courts are hearing workplace discrimination cases</li> <li>• Judicial officers are better equipped to reduce stigma and improve compliance with non-discriminatory labour standards in the workplace</li> </ul>
<p><b>Tanzania</b>  <i>HIV and AIDS Stigma-Reduction Community-Based Project in Tanzania</i>                      (stand-alone programme)</p> <p>Kimara Peer Educators and Health Promoters Trust Fund</p> <p>International Center for Research on Women  <a href="http://www.icrw.org">http://www.icrw.org</a></p> <p>Muhimbili University of Health Sciences  <a href="http://www.muchs.ac.tz/">http://www.muchs.ac.tz/</a></p> <p>Nyblade, L. et al. "Moving Forward: Tackling Stigma in a Tanzanian Community." <i>Horizons Report</i>. Washington, DC: Population Council, forthcoming 2007.</p>	Program staff, community leaders, People living with HIV and communities	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>• Held a training of trainers for programme staff using the research-based <i>Understanding and Challenging Stigma: A Toolkit for Action</i> to address gaps in staff knowledge and understanding of stigma and equip them with skills to carry out stigma-reduction activities</li> <li>• Held a training of trainers for 10 key influential community leaders to clarify and address knowledge gaps related to stigma and discrimination and develop action plans to integrate stigma and discrimination into ongoing activities</li> <li>• Integrated anti-stigma and discrimination messages and participatory activities into existing activities, including community dramas and home-based care visits</li> <li>• Held counseling groups for people living with HIV</li> <li>• Developed simple literacy brochures using images from the <i>Stigma Toolkit for Action</i></li> </ul>	<ul style="list-style-type: none"> <li>• Program staff effectively carried out stigma and discrimination activities in the community</li> <li>• Community leaders' attitudes and behaviours towards people living with HIV improved</li> <li>• Community-wide increase in the recognition of stigma</li> <li>• Community members exposed to the programme demonstrated less stigmatizing attitudes compared to those not exposed</li> <li>• Number of people living with HIV attending counselling groups increased</li> <li>• Demand for simple low literacy brochures is high</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>Thailand</b>  <i>Sangha Metta</i>                      (Compassionate Brethren)</p> <p><i>Project</i>                      (integrated programme)</p> <p><a href="http://www.buddhanet.net/sangha-metta/project.html">http://www.buddhanet.net/sangha-metta/project.html</a></p>	Buddhist monks, nuns, novices, people living with HIV, communities	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>• Trained Buddhist monks, nuns and novices in participatory management to engage community members in HIV prevention and support activities</li> <li>• Provided home-care assistance and financial and spiritual support for people living with HIV at home</li> </ul>	<ul style="list-style-type: none"> <li>• Increased numbers of people living with HIV are actively participating in community events and temple festivals</li> <li>• Community members are more accepting of people living with HIV (for instance, HIV-positive children are now admitted to schools where they were previously denied entrance)</li> <li>• Leaders in Christian, Hindu, and Islamic faiths have adopted the Sangha Metta training model for their own communities in neighbouring countries</li> </ul>
<p><b>Thailand</b>  <i>Thailand Business Coalition on AIDS</i>                      (stand-alone programme)</p> <p><a href="http://www.abcon aids.org/tbca/">http://www.abcon aids.org/tbca/</a></p> <p>Asian Business Coalition on AIDS  <a href="http://www.abcon aids.org">http://www.abcon aids.org</a></p>	Non profit organizations and business sector	<p><b>To challenge discrimination in institutional settings</b></p> <ul style="list-style-type: none"> <li>• Provided HIV prevention and stigma reduction training to businesses</li> <li>• Designed and implemented non-discriminatory policies and programmes for targeted industries</li> </ul>	<ul style="list-style-type: none"> <li>• Increasing numbers of businesses have adopted institutional workplace policies on HIV</li> <li>• HIV positive employees report an increased sense of acceptance and support in the workplace</li> <li>• Pilot programmes are now being conducted across Asia</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>Uganda</b>  <i>Uganda Workplace HIV/AIDS Prevention Project</i>            (integrated programme)</p> <p>RTI International  <a href="http://www.rti.org/">http://www.rti.org/</a></p> <p>Ssengonzi, R. (August 2007). Uganda Workplace HIV/AIDS Prevention Project (WAPP).  <a href="http://www.rti.org/pubs/rti_Uganda_HIV_brochure.pdf">http://www.rti.org/pubs/rti_Uganda_HIV_brochure.pdf</a></p>	<p>Informal sector workers (market vendors, transporters, shop attendants, etc)</p>	<p><b>To challenge discrimination in institutional settings</b></p> <ul style="list-style-type: none"> <li>Utilized community-based organizations and faith-based organisations to provide education and awareness campaigns for HIV prevention</li> <li>Provided informal health sector workers with health talks, drama, dialogue, testimonies from people living with HIV to mitigate stigma and its effects</li> </ul>	<ul style="list-style-type: none"> <li>Over 400 peer educators have been trained to provide HIV education to their co-workers in the informal market sector</li> <li>Over 800 education/ awareness training sessions have been conducted</li> </ul>
<p><b>Venezuela</b>  <i>Acción Ciudadana Contra el Sida (Citizen's Action against AIDS)</i>            (stand-alone programme)</p> <p><a href="http://www.internet.ve/accsi/">http://www.internet.ve/accsi/</a></p>	<p>People living with HIV and their families</p>	<p><b>To build human rights and legal capacity</b></p> <ul style="list-style-type: none"> <li>Provided free legal assistance to people living with HIV and their families</li> </ul>	<ul style="list-style-type: none"> <li>After ACCSI successfully defended individual claims for free antiretroviral treatment, the Supreme Court, in 1999, ordered the Ministry of Health to provide free antiretroviral treatment to all people living with HIV in Venezuela</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>Viet Nam</b>  <i>Reducing HIV/ AIDS-related Stigma and Discrimination</i>                      (stand-alone programme)</p> <p>Institute for Social Development Studies (ISDS)  <a href="http://www.isds.org.vn/home.asp">http://www.isds.org.vn/home.asp</a></p> <p>International Center for Research on Women (ICRW)  <a href="http://www.icrw.org">www.icrw.org</a></p> <p>Hong, Khuat Thu, Nguyen Thi Van Anh, and Jessica Ogden.  <i>Understanding HIV and AIDS-related Stigma and Discrimination in Vietnam</i>. Washington, DC: ICRW, 2004.  <a href="http://www.icrw.org/docs/vietnamstigma_0204.pdf">http://www.icrw.org/docs/vietnamstigma_0204.pdf</a></p>	Government officials and journalists	<b>To prevent and reduce stigma among different key audiences/ communities</b>	<ul style="list-style-type: none"> <li>• Personalized the issue of stigma and motivated policy makers and media to act</li> <li>• National party official requested further assistance in developing guidelines on media reporting that decrease stigma</li> <li>• A new AIDS law that focuses particularly on stigma and discrimination was instituted in Viet Nam</li> <li>• The programme allowed researchers to access provinces and communities that were previously unattainable</li> </ul>
		<ul style="list-style-type: none"> <li>• Promoted indirect and direct interaction between people living with HIV and key audiences to dispel myths about people affected by HIV</li> <li>• Inspired critical thinking and action through participatory workshops that tackled underlying attitudes that drive stigma</li> <li>• Engaged journalists and other communication professionals to steer away from sensationalized, fear-inducing coverage that perpetuated negative stereotypes and produce more accurate, positive portrayals of people living with HIV and AIDS</li> </ul>	
		<b>To challenge discrimination in institutional settings</b>	
<ul style="list-style-type: none"> <li>• Engaged policymakers in critical reflection about how they can enact policies to reduce stigmatization</li> </ul>			

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>Viet Nam</b>  <i>Reducing HIV/AIDS-related Stigma and Discrimination in the Healthcare Setting in Viet Nam</i>                      (stand-alone programme)</p> <p>Institute for Social Development Studies (ISDS)  <a href="http://www.isds.org.vn/home.asp">http://www.isds.org.vn/home.asp</a></p> <p>International Center for Research on Women (ICRW)  <a href="http://www.icrw.org">www.icrw.org</a></p> <p>“Reducing HIV/AIDS-related Stigma and Discrimination in the Healthcare Setting in Vietnam.” <i>Horizons Final Report</i>. Washington, DC: Population Council, forthcoming.</p>	<p>Hospital staff members (including health care workers, janitorial and administrative staff)</p>	<p><b>To challenge discrimination in institutional settings</b></p> <ul style="list-style-type: none"> <li>• Provided hospital health workers the opportunity to develop new guidelines for dealing with patient care for patients with HIV</li> <li>• Provided a safe environment for health workers to discuss fears and concerns about attending people with HIV and explore feelings and attitudes about people living with HIV</li> <li>• Trained health workers on universal precautions and infection control procedures</li> </ul>	<ul style="list-style-type: none"> <li>• Each hospital developed guidelines for patient care of patients with HIV</li> <li>• In-depth knowledge of HIV increased among hospital staff</li> <li>• Fear-based stigma reduced among hospital staff</li> <li>• Value-based stigma reduced among hospital staff</li> <li>• Decrease in inappropriate/overuse of barrier protection methods when attending to HIV positive patients.</li> </ul>
<p><b>Zambia</b>  <i>AIDS Integrated Programme</i>                      (integrated programme)</p> <p>Catholic Diocese of Ndola, AIDS Department</p> <p>Family Health International  <a href="http://www.fhi.org">http://www.fhi.org</a></p> <p>Boswell, D. and Banda, I. (2002) <i>Home and community care in Zambia: an external evaluation of the AIDS integrated programme, Catholic Diocese of Ndola</i>. Family Health International</p> <p>Blinkhoff P. et al (1999) <i>Under the Mpundu tree: volunteers in home care for people with HIV/AIDS and TB in Zambia’s Copperbelt</i>. Actionaid: Strategies for Hope series no. 14.  <a href="http://www.stratshope.org/b-mupundu.htm">http://www.stratshope.org/b-mupundu.htm</a></p>	<p>Chronically ill patients and their families</p>	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>• Provided integrated, home-based care for adults living with TB and HIV</li> <li>• Strengthened the capacity of communities and families to provide care for people living with HIV</li> </ul>	<ul style="list-style-type: none"> <li>• Programme participation, which includes HIV testing, has increased rapidly</li> <li>• Family neglect has decreased</li> <li>• Volunteers report less fear and less associated stigma</li> </ul>

<b>Programme</b> (Location, Title, Type of Program <sup>3</sup> , Implementing Agency, References)	<b>Target Audience</b>	<b>Key Activities by Objective<sup>4</sup></b>	<b>Outcomes</b>
<p><b>Zambia</b>  <i>Involving Young People in the Care and Support of People Living with HIV</i> (integrated programme)</p> <p>Horizons Program                      (Population Council)  <a href="http://www.popcouncil.org/horizons">http://www.popcouncil.org/horizons</a></p> <p>CARE International/ Zambia  <a href="http://www.careinternational.org.uk/?lid=3376">http://www.careinternational.org.uk/?lid=3376</a></p> <p>Family Health Trust</p> <p>Esu-Williams, E., et al. "Involving People in the Care and Support of People Living with HIV/AIDS in Zambia." <i>Horizons Final Report</i>. Washington, DC: Population Council, 2004.  <a href="http://www.popcouncil.org/pdfs/horizons/zmbcsythfnl.pdf">http://www.popcouncil.org/pdfs/horizons/zmbcsythfnl.pdf</a></p>	<p>People living with HIV and their families</p>	<p><b>To prevent and reduce stigma among different key audiences/ communities</b></p> <ul style="list-style-type: none"> <li>• Youth were trained to be adjunct family caregivers to strengthen the capacity of communities and families to provide care for people living with HIV</li> <li>• Trained youth visited families once or twice a week</li> <li>• Youth modelled care giving behavior and emphasised that daily contact with people living with HIV is not "risky"</li> </ul>	<ul style="list-style-type: none"> <li>• Youth caregivers felt comfortable assisting families in household chores, cleaning sores, counselling families about HIV, and referring family members to clinics</li> <li>• Clientele perceived positive changes in behaviour and attitudes among caregivers and the community at large</li> <li>• Family members of people living with HIV became more involved in caregiving</li> </ul>

## ANNEX B

### Measuring Stigma and Discrimination

**One of the major obstacles hampering further progress in the reduction of stigma and discrimination is the lack of monitoring and evaluation data.** At the national level, understanding the causes and impacts of stigma and discrimination is key to “knowing your epidemic”. At the programme level, assessing the progress and impact of stigma-reduction interventions is essential for identifying best practices and scaling-up stigma/discrimination reduction activities. While both national and programme-level monitoring and evaluation data on stigma/discrimination and reduction efforts are crucial for halting the spread of HIV and increasing uptake of care and treatment services, they are often neglected in National Monitoring and Evaluation Frameworks. National AIDS programmes, with support from UNAIDS and United Nations Joint Teams on AIDS, should incorporate stigma and discrimination into these frameworks and build the capacity of national advisors and programme managers to measure and report on stigma and discrimination-related outcomes.

#### *Knowing your epidemic*

In order for countries to mount a successful campaign against HIV, National Coordinating Authorities must understand the particular dynamics of their own epidemic or sub-epidemics. Most countries collect and report data on HIV incidence and prevalence in an attempt to know their epidemic; however this data only provides a piece of the puzzle. **In addition to epidemiologic data, it is essential that countries understand the causes and impacts of their epidemic.** One key driver of the epidemic is stigma and discrimination related to HIV. It is important that National Coordinating Authorities recognize the relevance of national-level data on stigma and discrimination and actively incorporate stigma and discrimination indicators into their annual monitoring and reporting efforts.

Measuring stigma and discrimination at the national-level is supported by the UNGASS commitments. Currently, stigma and discrimination are included in the UNGASS National Composite Policy Index.<sup>5</sup> While it is important to ensure that anti-stigma/discrimination policies and laws are in place, understanding the underlying causes of stigma/discrimination is necessary for developing strategies and programs to reduce them. A set of indicators to measure these aspects at the population level have recently been validated.<sup>6</sup> In addition, the People Living with HIV Stigma Index, which documents the stigma and discrimination experienced by HIV-positive people, has recently been validated.<sup>7</sup> National AIDS programmes should support the collection of these data and integrate into the National Monitoring and Evaluation Framework to enable National Coordinating Authorities to fully know their epidemic.

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5 UNAIDS. Monitoring the Declaration of Commitment on HIV/AIDS: Guidelines on Construction of Core Indicators: 2008 Reporting. [http://data.unaids.org/pub/Manual/2007/20070411\\_ungass\\_core\\_indicators\\_manual\\_en.pdf](http://data.unaids.org/pub/Manual/2007/20070411_ungass_core_indicators_manual_en.pdf)

6 Tanzania stigma-indicators field testing group, *Measuring HIV Stigma: Results of a Field Test in Tanzania*. 2005, Synergy: Washington, DC. [http://www.synergyaids.com/documents/StigmaIndicatorsReportFinal\\_JuneEdited.pdf](http://www.synergyaids.com/documents/StigmaIndicatorsReportFinal_JuneEdited.pdf)

7 For background on the development of the PLHIV Stigma Index, see: UNAIDS, *Meeting on development of index on human rights, stigma and discrimination by and for people living with HIV*. 2005: Geneva. [http://data.unaids.org/UNA-docs/meeting\\_hr\\_plhivindex\\_23aug05\\_en.pdf](http://data.unaids.org/UNA-docs/meeting_hr_plhivindex_23aug05_en.pdf)

## Monitoring and evaluating stigma reduction interventions

To date, few stigma/discrimination-reduction interventions have been evaluated. This gap may have been due to the paucity of tested and validated programme measures for stigma. However, measures to assess programmes are now available and it is essential, given the nascent nature of stigma/discrimination-reduction programming, that careful evaluation is conducted to identify effective models for replication and scaling-up.<sup>8</sup>

**Tested, reliable and validated measures are now available to help assess the underlying causes of stigma and extent of discrimination experienced by people living with HIV, and found at the community and health provider-levels.**<sup>9</sup> Examples of such measures include:

- 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 in Tanzania. Distinct questions have been developed to measure these three domains among the general population, health providers, and people living with HIV. A shortened list of tested indicators for the community-level is outlined in the table below.
- Indicators to capture the experience of stigma from the perspective of people living with HIV, including the presence of internalized-stigma and the ability to safely disclose status and access needed care, support and treatment.
- The People Living with HIV Stigma Index – developed by and for people living with HIV – to document the stigma and discrimination experienced by positive people and inform advocacy and programmes to address stigma.

## Integrating monitoring and evaluation into stigma/discrimination-reduction programmes<sup>10</sup>

Monitoring and evaluation should be key elements of HIV programming, whether programmes are focused on stigma/discrimination-reduction, or incorporate such work into HIV prevention, treatment, care and support programmes. In assessing proposed or ongoing measurement efforts, the following questions and considerations may prove useful:

- **Does the programme include monitoring and evaluation of stigma/discrimination-reduction?**
- **Are the proposed measures appropriate for what the programme seeks to accomplish?** In particular, what dimensions of stigma/discrimination is the programme seeking to change (e.g. fear of transmission through casual means, attitudes underlying stigma like homophobia) and will the proposed measures capture these?

8 Nyblade, L. and K. MacQuarrie, Can We Measure HIV/AIDS-related Stigma and Discrimination? Current knowledge about quantifying stigma in developing countries. 2006, USAID: Washington, DC. [http://www.icrw.org/docs/2006\\_CanWeMeasureHIVstigmaReport.pdf](http://www.icrw.org/docs/2006_CanWeMeasureHIVstigmaReport.pdf)

9 Tanzania stigma-indicators field testing group, *Measuring HIV Stigma: Results of a Field Test in Tanzania*. 2005, Synergy: Washington, DC. [http://www.synergyaids.com/documents/StigmaIndicatorsReportFinal\\_JuneEdited.pdf](http://www.synergyaids.com/documents/StigmaIndicatorsReportFinal_JuneEdited.pdf)

10 This section adapted from DFID. *Taking Action Against Stigma*, forthcoming.

- **Does the proposed evaluation recognize that different dimensions of stigma/discrimination need to be measured separately?** An intervention may affect different dimensions of stigma/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 or discrimination by addressing one or more underlying causes (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 or 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 causes of stigma; reductions in stigmatising and discriminating behaviours; 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 self-stigma and other aspects of empowerment. The measures should not, for example, focus on stigma or discrimination in the general population. On the other hand, interventions at the home, community or healthcare level will need to measure change in stigma/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 organization'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/discrimination on outcome variables such as uptake in services requires substantial investment and expertise. However, focusing on measuring reductions in the causes of stigma/discrimination, or stigma/discrimination alone, either through quantitative or qualitative assessment, can provide solid evidence of a programme's progress.

**Table 1 – Items that can be used to assess stigma at the community-level**

<b>Fear</b>
Fear of HIV transmission through day-to-day contact can be assessed by asking whether individuals fear contracting HIV:
<ul style="list-style-type: none"> <li>• if they touch the saliva of a person with HIV or AIDS</li> <li>• if they touch the sweat of a person with HIV or AIDS</li> <li>• if they touch the excreta of a person with HIV or AIDS</li> <li>• [that their child would become infected with HIV] if they play with a child who has HIV or AIDS</li> <li>• if they eat food prepared by a person with HIV or AIDS</li> </ul>
<b>Shame and Blame</b>
Stigma and discrimination based on shame, blame and judgement can be determined by assessing agreement with the following statements:
<p><b>Shame</b></p> <ul style="list-style-type: none"> <li>• I would feel ashamed if I was infected with HIV.</li> <li>• People with HIV or AIDS should be ashamed of themselves.</li> <li>• I would be ashamed if someone in my family had HIV or AIDS.</li> </ul>
<p><b>Blame and Judgment</b></p> <ul style="list-style-type: none"> <li>• It is the women prostitutes that spread HIV in our community.</li> <li>• HIV is a punishment for bad behaviour.</li> <li>• People with HIV or AIDS are promiscuous.</li> <li>• HIV is a punishment from God.</li> </ul>
<b>Discrimination (enacted stigma)</b>
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:
<p><b>Isolation (including physical and social exclusion)</b></p> <ul style="list-style-type: none"> <li>• Excluded from a social gathering</li> <li>• Abandoned by partner</li> <li>• Abandoned by family/sent away</li> </ul>
<p><b>Verbal stigma</b></p> <ul style="list-style-type: none"> <li>• Teased, insulted, sworn at</li> <li>• Gossiped about</li> </ul>
<p><b>Loss of identity/role</b></p> <ul style="list-style-type: none"> <li>• Lost respect/standing within the family and/or community</li> </ul>
<p><b>Loss of access to resources or services</b></p> <ul style="list-style-type: none"> <li>• Lost customers or a job</li> <li>• Had property taken away</li> <li>• Denied health care services, social services or education</li> </ul>

## ANNEX C

### Resources for Conducting Stigma and Discrimination-reduction Activities<sup>11</sup>

**Tools and Manuals** The following table presents tools and manuals that practitioners may use or adapt to conduct anti-stigma and discrimination activities.

Selected Tools				
	Description	Audience/s	Countries of use	For More Information
<b>Toolkit</b>				
<i>Understanding and Challenging HIV Stigma toolkit</i>	Toolkit consisting of 11 modules and more than 125 participatory exercises that can be used for participatory education interventions and workshops.	Broad: communities, religious leaders, politicians, educators, community leaders, service providers, journalists, people living with HIV. New module for men who have sex with men.	Botswana, Côte d'Ivoire, Ethiopia, Ghana, India, Kenya, Mozambique, Nigeria, Senegal, Tanzania, Uganda, Viet Nam, Zambia. Module for men who have sex with men developed in Senegal and Tunisia.	International Center for Research on Women <a href="http://www.icrw.org">www.icrw.org</a>  International HIV/AIDS Alliance: Supporting Community Action on AIDS in Developing Countries <a href="http://www.aidsalliance.org">www.aidsalliance.org</a>
<b>More targeted tools</b>				
<i>'The truth about AIDS. Pass it on...</i>	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 <a href="http://www.ifrc.org/what/health/hivaids/antistigma/">www.ifrc.org/what/health/hivaids/antistigma/</a>  The Campaign was produced in partnership with GNP+
<i>Reducing Stigma and Discrimination Related to HIV and AIDS: Training for Health Care Workers.</i>	Consists of a participant's handbook, a trainer's manual, and <i>Infection Prevention: A Reference Booklet for Health Care Providers</i>	Health workers	Bangladesh, Ethiopia, Ghana, India, Kenya, Nigeria, and Tanzania	EngenderHealth <a href="http://www.engenderhealth.org">www.engenderhealth.org</a>

11 Adapted from DFID. *Taking Action against Stigma*, forthcoming, 2007.

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

## **Understanding and Challenging HIV Stigma toolkit**

*Understanding and Challenging HIV Stigma*<sup>12</sup> is the most comprehensive toolkit presently available to address stigma 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. The toolkit has a flexible menu of modules (see table below for more details) and can be used to engage a range of audiences, including health workers, business leaders, educators, policymakers, religious leaders, people and the media. People living with HIV can be both audience members and implementers of the toolkit. Knowing stigma from the “inside,” this group can play an important role as stigma trainers. At the same time they need help to cope with stigma and self-stigma. One of the chapters in the toolkit, provides exercises for people living with HIV, aimed at strengthening their own understanding of stigma and empowering them to challenge stigma.

The toolkit has been translated into a number of languages including Amharic, French, Portuguese, and Swahili, and adapted versions of the toolkit have been translated into Telugu and Vietnamese. Given its wide applicability and field-based content, the toolkit provides a cost-effective way for addressing stigma. National AIDS programmes and their partners can adapt toolkit activities and integrate into existing programmes or use in “stand-alone” efforts.

12 Available at: <http://www.icrw.org/html/issues/hiv aids.htm>

## How Is The *Understanding and Challenging HIV Stigma* Toolkit Organised?

Module	Title	Target Group	No. of Exercises	Theme or Contents
A	<b>Naming the Problem</b>	General	9	Identify forms of stigma in different settings. Describe the forms, effects and causes of stigma. Build recognition that stigma exists and hurts PLHIV, families, etc; and fuels the epidemic.
B	<b>More Understanding, Less Fear</b>	General	6	Explore fears about getting HIV through casual contact. Discuss how these fears are based on inadequate understanding on 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	<b>Sex, Morality, Shame &amp; Blame</b>	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 to feelings about sex and gender.
D	<b>The Family and Stigma</b>	General	11	Exploring stigma in a family setting – forms and effects of stigma in the family.
E	<b>Home Based Care &amp; Stigma</b>	Home based care workers	6	Exercises for use with home based care workers – professionals and volunteers. Aim – to reduce stigma within their working context
F	<b>Coping with Stigma</b>	People living with HIV	13	The aim is to strengthen people living with HIV by helping them overcome self-stigma, cope with stigma, rebuild their self-esteem, and develop skills to take leadership roles in anti-stigma education and action.
G	<b>Treatment and Stigma</b>	Health workers	12	Exploring the ways in which stigma is a barrier to ARV treatment, including adherence.
H	<b>Men who have sex with men and Stigma</b>	Men who have sex with men	7	This module looks at the 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	<b>Moving to Action</b>	General	12	Reviewing the lessons learned and then applying them to one’s own context. Participants develop actionable strategies, and plan specific activities to challenge stigma.
J	<b>Children and Stigma</b>	Orphans and vulnerable children	21	Looks at the stigma faced by orphans, street children, children living with HIV, and other vulnerable children. Exercises for guardians to help them understand the feelings of these children; and exercises for children to help them deal with feelings and the impact of stigma.

Module	Title	Target Group	No. of Exercises	Theme or Contents
K	<b>Youth and Stigma</b>	Youth workers	16	Explores the stigma faced by young people and how they are affected by judgments 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 faced by young people.

## ANNEX D

### Key points for advocacy on HIV stigma and discrimination<sup>13</sup>

#### ***Stigma and discrimination threaten effective responses to HIV.***

- Stigma and discrimination are primary obstacles to scaling up HIV prevention, treatment, care and support.
- Fear of stigma and discrimination make people less likely to adopt HIV preventive behaviour, less likely to get tested, and less likely to disclose their HIV status to partners and caregivers.
- Stigma and discrimination are connected with postponing or rejecting care, and non-adherence to HIV treatment and medicines.

#### ***Addressing stigma and discrimination must be an integral part of “knowing your epidemic” and responding to it in the national AIDS response.***

- Comprehensive action against stigma and discrimination is critical for scaling up HIV-related services, including prevention and antiretroviral treatment programmes.
- To accomplish this, national AIDS programmes must:
  - Include stigma and discrimination comprehensively throughout national AIDS strategic plans and annual action plans;
  - Prioritize strategic planning for scaling-up stigma and discrimination-reduction activities;
  - Support key stakeholders to conduct stigma and discrimination reduction activities.

#### ***The three main causes of stigma and discrimination can be addressed programmatically.***

- Lack of awareness of stigma and discrimination and their harmful effects;
- Fear of acquiring HIV through everyday contact; and
- Linking people with HIV to behaviour considered improper or immoral.

#### ***There are a number of proven strategies by which to address stigma and discrimination.***

- Empower people living with HIV and other vulnerable groups to know and assert their rights.
- Enlist public figures, including religious leaders, to advocate against stigma and discrimination.
- Promote laws and legal support to protect the rights of people living with HIV and other vulnerable groups.

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<sup>13</sup> Adapted from DFID. *Taking Action against Stigma*, forthcoming 2007.

- Support community-based efforts that foster critical thinking and inspire behaviour change.
- Promote anti-stigma initiatives among health care providers, police, the judiciary, journalists, and educators.

***There are a number of proven anti-stigma and discrimination tools which are available:***

- The *Understanding and Challenging HIV Stigma*<sup>14</sup> toolkit, can be used to reduce stigma and discrimination with multiple audiences.
- A “PLHA-friendly” checklist<sup>15</sup> is available to help health care institutions reduce discrimination.
- The People Living with HIV Stigma Index<sup>16</sup> – developed by and for people with HIV – is available to assess common forms of discrimination faced by people with HIV.

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14 Available at: <http://www.icrw.org/html/issues/hivaids.htm>

15 Available at: [www.popcouncil.org/horizons](http://www.popcouncil.org/horizons)

16 See Box 3 above. For further information on the PLHIV Stigma Index, contact K. Thomson, UNAIDS Geneva, [thomsonk@unaid.org](mailto:thomsonk@unaid.org).

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UNAIDS, the Joint United Nations Programme on HIV/AIDS, brings together the efforts and resources of ten UN system organizations to the global AIDS response. Cosponsors include UNHCR, UNICEF, WFP, UNDP, UNFPA, UNODC, ILO, UNESCO, WHO and the World Bank. Based in Geneva, the UNAIDS secretariat works on the ground in more than 80 countries worldwide.

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*Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes* outlines strategies and programmes for overcoming stigma and discrimination, which are recognised as major obstacles to achieving Universal Access to HIV prevention, treatment, care and support by 2010. It is designed to be used by national AIDS programme staff, civil society groups, media, development partners, UN staff, and national human rights institutions, and includes an overview of 25 successful national and regional programmes to address stigma and discrimination.



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