Towards a Stronger Response to HIV and AIDS: Challenging Stigma

We are really living under the fear of discrimination...it has silenced us...because of this we cannot take care of ourselves and others.”

- Ethiopian woman living with HIV [3]

For the past 20 years, experts and researchers have identified stigma as a central contributor to the HIV pandemic. This paper provides information and evidence on the following key messages:

- HIV stigma is globally prevalent and damaging—affecting people living or associated with HIV and AIDS on a daily basis—and is especially severe for women;
- HIV stigma compromises effective responses to AIDS. It lowers uptake of preventive services and testing, delays disclosure, decreases care seeking and undermines treatment;
- Effective strategies for tackling stigma exist, and action is possible; and
- DFID is well placed to help scale-up efforts and play a leading role in the international arena.

Background

In countries worldwide, stigma—defined broadly as prejudice, discounting, discrediting and discrimination—is a daily reality for people living with HIV and AIDS and their families. It also affects groups closely associated with the disease, including sex workers, men who have sex with men, injecting drug users and prisoners. Stigma not only adds to their burden, but functions as a key barrier to effective prevention, treatment, care and support.

The 2006 Political Declaration adopted at the U.N. High Level Meeting on AIDS notes that addressing stigma and discrimination is “...a critical element in combating the global HIV/AIDS pandemic.”[4] More specifically, stigma has been cited as a major barrier to achieving the goal of universal access to comprehensive HIV prevention programmes, treatment, care and support by 2010. Through the 2006 Political Declaration, U.N. member states committed to “eliminate all forms of discrimination against people living with HIV and members of vulnerable groups... and developing strategies to combat stigma and social exclusion connected with the epidemic”[4].

Despite stigma’s pervasiveness and centrality, stigma remains neglected in country responses to HIV and AIDS [5]. As Peter Piot, UNAIDS executive director, pointed out in his keynote address at the recent International AIDS Conference:

...there has never been serious political and programmatic commitment to doing anything about [HIV stigma]. All these efforts have been relegated to the bottom of AIDS programmes, together with human rights, and often with no funding attached to them [6].

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1 In this paper, we do not conceptualize discrimination as separate from stigma, but as the end result of the process of stigma—in effect, “enacted” stigma. We define discrimination as the negative acts that result from stigma and that serve to devalue and reduce the life chances of the stigmatized.
Dimensions of HIV Stigma

HIV stigma is globally prevalent, pervasive and damaging [7-14]. Worldwide, researchers have documented that people living with HIV are subject to job loss, school expulsion, ostracism, violence, lack of care and support, and loss of property. Stigma is not a rare or isolated event. In a recent study in Tanzania, 56 percent of respondents living with HIV had recently experienced stigma, and 59 percent of health providers surveyed observed stigma at their jobs [15]. Stigma also operates at multiple levels: within families, communities, institutions such as health care facilities and places of employment, in the media, and in government policies [2, 13].

Researchers have found evidence of stigma in settings as diverse as China, Mexico, South Africa and the United States [16-20]. Stigma exists in high prevalence settings such as Botswana and in lower prevalence settings such as India [21, 22]. Further, a comparative study conducted in rural and urban sites in Ethiopia, Tanzania, Vietnam and Zambia found stigma was remarkably consistent across contexts in forms, consequences and key drivers [13]. The three key actionable drivers of stigma are: lack of awareness and knowledge of stigma; fear of acquiring HIV through everyday contact with infected people; and values linking people with HIV with behaviour considered improper and immoral.

HIV stigma is often layered, building upon and reinforcing existing prejudices and inequalities [5, 23]. Groups that experience multiple forms of stigma include injecting drug users, sex workers, men who have sex with men and prisoners. Because its effects are magnified by gender, race, sexuality and other factors, stigma tends to be most debilitating for people already vulnerable and marginalised, who are often the most affected by HIV and AIDS and who tend to be neglected in national responses and by donors. Numerous studies have shown, for instance, that women tend to experience greater stigma than men, are more likely to experience its harshest and most damaging forms, and have fewer resources for coping with it [10, 13, 14, 24-26]. Violence is a particularly harsh form of stigma faced principally by women [27-32]. People who are already stigmatised often face increased discrimination when diagnosed with HIV, including refusal of services, which heightens the challenges of meeting the needs of people at greatest risk for acquiring HIV [25, 33-37].

In terms of public health outcomes, stigma in health care settings is particularly damaging. Numerous studies document that health care providers discriminate against people who are HIV-positive [2, 7, 26, 38-40]. In India, for example, a survey of health care workers found only 39 percent sought informed consent for testing [22]. In a survey of health care professionals in Nigeria, 43 percent observed others refusing hospital admission to a patient with HIV [41]. Providers are not immune to HIV stigma, which can deter them from testing and care seeking and further erode human capital and the ability to provide care.

“Neighbors will tell me there is a sick person in the bedroom at the back of the house. But when I arrive the family denies having such a person. The families themselves prevent anyone from helping them.”
- Community health care worker providing AIDS care in KwaZulu-Natal province, South Africa [1]

Stigma Compromises Effective Responses to HIV and AIDS

Achieving the ambitious international goals set forth for HIV and AIDS will require rapid scale-up of services. To ensure that investments in the supply of services are maximised, demand-side barriers such as stigma need to be addressed. Stigma represents a major “cost” in the calculus of individual decision making related to preventive behaviour and care seeking. Various studies indicate stigma is associated with lower uptake of preventive services, including under- or non-participation in educational meetings and counselling [42]; lower intention to take preventive measures [43]; and reduced participation in programmes to prevent mother-to-child transmission [44, 45]. In countries ranging from Jamaica to Zambia, researchers have found numerous instances where fear of stigma deters people from getting tested [11, 45, 46].

Even the widespread availability of treatment does not necessarily diminish stigma or lead to greater
testing levels. In 2002, Botswana became the first African country to launch a national antiretroviral treatment programme. Despite the nation’s commitment to universal access to treatment, enrolment in its Masa ARV Therapy Programme lagged. The government identified HIV stigma as a major barrier to participation [21, 47].

Stigma adversely affects disclosure of serostatus to partners, providers and family members. Disclosure, however, is crucial to outcomes ranging from condom use to care seeking. Among people who test seropositive, a number of studies have documented non-disclosure due to fear of stigma [21, 37, 48-50]. In China, a study found that patients with sexually transmitted infections who felt stigmatised were less likely to agree to notify their spouse [16]. A Tanzania study among persons living with HIV found only half of respondents had disclosed their status to intimate partners. Among those who disclosed, the average time from knowing to disclosure was 2.5 years for men and 4 years for women [15].

Gender-based violence related to HIV status, a particularly harsh form of stigma, also affects HIV prevention and service provision. Both women and girls report increased violence for requesting condom use; accessing voluntary testing and counselling; refusing sex within or outside marriage; or for testing HIV-positive [27, 54-60].

Promising Strategies for Tackling Stigma

All major donors recognize that reducing stigma is crucial in the response to HIV and AIDS. This is reflected both in stated commitments and, to a lesser extent, action. The most common response to date has been to fund a range of small, somewhat ad hoc, efforts, which are rarely evaluated. Among the barriers to greater involvement are the perceptions that stigma is too culturally specific and complicated to address, and that knowledge remains insufficient for effective action.

Although knowledge gaps remain, researchers and practitioners have set the stage for effective, scaled-up interventions that can generate broad reductions in stigma. In settings as varied as India, Tanzania and Vietnam, practitioners have developed practical tools for stigma-focused interventions [61] and implemented successful interventions with a range of target groups [62-65]. Given that stigma is remarkably consistent across contexts in forms, consequences and key drivers, practitioners could devise a common core response to stigma with minor modifications by setting.

“As stigma is a social construct and not an attribute of individuals, we must not expect persons affected alone to carry the burden of activism against stigma or that educating the general public and increasing their tolerance is enough.”
- Heijnders & Van Der Meij [2]

An effective, scaled-up response to stigma will consider the short- and long-term. A long-term perspective is necessary because changing values, norms and societal structures such as legal frameworks take time. But much can be accomplished in the short-term, with visible results, while also contributing to the long-term changes. Key principles for addressing the drivers of stigma include:

- Creating an awareness of what stigma is and the benefits of reducing it;
- Fostering motivation for change;
- Addressing fears and misconceptions about casual transmission;
- Discussing ‘taboo’ topics including gender, violence, sexuality and injecting drug use; and
- Providing the skills to challenge stigma and to change behaviour[13, 66].

These principles apply to any target group and are implemented most effectively through participatory methodologies.
Table 1: Successful Interventions to Reduce Stigma

| Address key underlying drivers | Interventions need to address the root causes of stigma rather than just its effects. Key drivers are lack of awareness, fear and values. Change is unlikely without understanding and reflection about what stigma is and why it is damaging. Fear of acquiring HIV through everyday contact leads people to take unnecessary and often stigmatising actions. Value-driven stigma links people with HIV to behaviour considered improper and immoral, thus justifying discrimination. |
| Understand that stigma operates at multiple levels | These levels include: individual, family, community, organizational/institutional, and government/legal. |
| Engage multiple target groups and potential change agents | These might include: opinion leaders (e.g., politicians, faith-based leaders), front-line HIV responders (e.g., health care workers, NGO and CBO workers), people living with HIV and other stigmatised groups, communities, the media, businesses, schools, police and the judiciary. |
| Employ a range of approaches | Successful approaches will involve a combination of the following: • Participatory and interactive education; • Strengthening and building capacity of stigmatised individuals and groups (e.g., through skills-building, network building, counselling, training, income generation); • Contact or interaction with people living with HIV and other stigmatised people (e.g., men who have sex with men and sex workers); • Mass education (e.g., media campaigns and edutainment programs); • Institutional reform (e.g., addressing discrimination in workplaces, health caresettings, schools and other institutions); • Policy dialogue and legal and policy reform together with enforcement, education and mechanisms for redress, especially at local levels; and • Provision of services, care and treatment (e.g., VCT, ARV therapy). |

There are two overarching lessons to date.

1) Interventions need to address the underlying drivers of stigma through a range of approaches and to operate at multiple levels with multiple target groups (see Table 1). This is critical to creating an enabling environment allowing individuals to practice prevention and access services. Stigma and underlying norms governing gender, sexuality and other factors are often enforced at the family, community, institutional, and legal and policy levels. Thus, interventions that operate at one level, focus on one target group or use only one approach are less apt to be effective. For example, educational strategies that aim to improve knowledge are common. Various studies, however, suggest these strategies, when used alone, have limited effectiveness [11, 17, 42, 43].

2) Action is possible. Although evaluation data are limited, multiple examples demonstrate the results of effective targeted interventions [1, 2, 52, 67-72]. Lessons learned from these efforts provide solid building blocks for a broader, scaled-up response to stigma. In a recent review of interventions, researchers conclude the most promising approaches to stigma reduction include a combination of empowerment of and contact with people living with HIV and education [73]. Participatory education—which encourages people to reflect on their own attitudes and actions—is especially effective for catalysing individual change around stigma at any level, but in particular at the community level [13, 74]. The power of these interventions is magnified in settings with enforceable laws and policies and available treatment and services.

A participatory approach is at the core of several promising stigma-reduction interventions [61]. These are being implemented in diverse settings, with change agents including communist party officials in Vietnam; teachers in Zambia, and health care workers in India, Tanzania and
This model uses interactive workshops with reflection exercises, role-plays, and discussions. These foster greater understanding of the harm stigma causes 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 workshops. Action planning is an important end result. This type of workshop led leaders of the Commission for Ideology and Culture of the Communist Party in Vietnam, which controls all media and party messaging, to formulate a set of media guidelines on conducting non-stigmatizing reporting on HIV and AIDS [65]. Participatory training has also generated ripple effects on stigma in the wider community. For instance, after undergoing training, a local political leader in Kimara, Tanzania successfully rallied her community to stand up against property grabbing by the relatives of children orphaned through AIDS (personal communication, 2006).

**DFID’s Involvement in Stigma Reduction**

A recent audit indicates that DFID supports about 100 projects and programmes addressing AIDS-related stigma and discrimination [78]. These efforts span three major approaches, including preventing and reducing stigma; challenging stigma in institutional settings; and promoting and protecting human rights. Most of DFID’s activities fall under the first approach and focus on reducing stigma associated with AIDS and/or high-risk behaviours. Specific activities include education and awareness campaigns, empowering excluded groups to advocate for improved services, and mobilising role models to foster openness and respect. Substantially fewer projects address discrimination in institutions such as workplaces and health care settings or the enforcement of laws and regulations protecting the rights of people living with HIV.

The majority of DFID’s support for stigma reduction goes to Africa, primarily in the form of mass media campaigns. In Asia, Latin America and the Caribbean, more programmes focus on the empowerment of excluded groups. In light of the latest research conclusions, these programmes are especially promising. Particularly noteworthy is Latin America’s Champions for Change programme, which operates at different levels and with different target groups to reduce stigma, discrimination and homophobia.

Among its activities was a conference where religious and political leaders engaged directly with people living with HIV [72].

While DFID is tackling stigma in a variety of ways, the audit suggests DFID is still not giving this area the attention it merits, considering the scale of the problem and the commitments made in “Taking Action.” Further, the most recent International Development Committee report on HIV and AIDS recommends that DFID ensure that “all national programmes it supports address stigma and discrimination…” The audit suggests a number of promising directions for future funding. These include expanding support for challenging discrimination in institutions such as health care settings and workplaces; for the enforcement of laws and regulations protecting the rights of people living with HIV and AIDS; and for organizations of people living with HIV.

DFID country offices support a number of organizations of people living with HIV and AIDS. And recently, DFID has stepped up its regional and global support in this area, providing funding for the International Community of Women Living with HIV and AIDS, Global Network of People Living with HIV/AIDS (GNP+), and the International Treatment Preparedness Coalition [78]. Given the importance of these groups, however, more support should be provided. Half of country offices responding to a recent questionnaire suggested DFID’s future anti-stigma efforts should support greater involvement of people living with HIV in programmes, policies and funding decisions [72]. A major challenge will be to identify ways DFID can more readily support these groups through its current aid instruments [79].

More generally, DFID can build on its considerable experiences to address gaps in programming and knowledge. With more than 100 anti-stigma programmes and models such as Champions for Change, DFID can help advance efforts towards a scaled-up approach to stigma reduction. Magnifying the impacts of current targeted efforts is key. Another challenge is to craft a multi-level, multi-approach response over a long enough period to effect change. This would help strengthen the evidence base regarding effective interventions, a critical need. The field would also benefit from more quantified information about the relationship between stigma and public health outcomes.
Conclusion

The need for action on stigma is globally recognized. Entities such as UNAIDS, the World Bank, the G8 countries, and others have all recommended a more concerted, robust response to stigma. Translating these recommendations into greater action is key. The relative neglect of stigma represents a critical gap, and has hampered an effective response to HIV and AIDS. DFID is in a strong position to fill this gap and play an instrumental role as issue leaders in the international arena. With a breadth and depth of programme experiences and a rights-based approach to HIV and AIDS, DFID is poised to support greater action in this area. The focus on universal access and the roll out of anti-retroviral therapy provide ready opportunities for DFID to address stigma, as do country-level policy and programme reviews on HIV and AIDS. By strengthening and scaling up the response to stigma, DFID could greatly improve the global effectiveness of investments in prevention, care, support and treatment.

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