Scaling Up *the* Response *to* HIV Stigma *and* Discrimination

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London School of Hygiene & Tropical Medicine

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

– Edward Cameron, Constitutional Court Justice in South Africa[1]

HIV stigma and discrimination* adversely affect every aspect of life for people living with HIV and their families. In many settings, an HIV diagnosis still can be as devastating as the illness itself, leading to job loss, school expulsion, violence, social ostracism, loss of property, and denial of health services and emotional support. People living in fear are less likely to adopt preventive behavior, come in for testing, disclose their sero-status to others, access care and adhere to treatment.

Reducing stigma and discrimination can dramatically improve the lives of people affected by HIV. With more than 33 million people living with the virus and an estimated 2.7 million new infections in 2008,[2] the need for intensified action has never been greater.

Scaling up current efforts to reduce stigma would also optimize investments in HIV prevention, care and treatment. For example, new estimates suggest that an effective stigma reduction program could result in significantly more mothers using HIV services and adhering to HIV treatments, potentially reducing mother-to-child transmission by as much as one-third in settings where stigma is prevalent.[3]

The challenge to expansion is that most efforts to address stigma are still small scale or in a pilot phase, and securing ongoing funding for programs remains a serious challenge.[3] Therefore, sustained advocacy is needed to push for increased resources to scale up stigma-reduction efforts directed at families, communities, institutions and governments.

This brief lays out the rationale for intensified action and what can—and must—be done to reduce HIV stigma and discrimination worldwide.

* *Stigma* is defined broadly in this paper and encompasses discrimination or "enacted stigma." For greater clarity, however, the two are often mentioned together in the text.

I. Why Action Is Needed

"I am afraid of coming [to the health center]—more people will learn of my HIV status and my in-laws will learn it too."

– Vietnamese woman living with HIV[23]

HIV stigma and discrimination are a daily reality for people living with HIV and their families. Stigma is prevalent in diverse contexts from Brazil to Zimbabwe.[4-12] Stigma is strong both in higher HIV prevalence settings such as Botswana as well as in lower prevalence countries such as India.[13, 14] It also operates within families; communities; institutions such as health care facilities and places of employment; the media; and government policies, laws and legislation.[15-17]

Stigma takes on multiple forms, which are all damaging. People living with HIV experience stigma in numerous forms, as illustrated in Table 1. Social stigma excludes people living with HIV from family and community events, resulting in their loss of power and respect in the community. Physical stigma includes isolation (such as separate sleeping quarters in the home or a separate seating area in places of worship) and violence. Verbal stigma includes insults, taunts, blame, gossip and rumors. Institutional stigma includes job loss due to HIV status, eviction from housing, loss of educational opportunities and substandard health care.[17]

HIV stigma tends to heighten existing prejudices. Vulnerable groups, such as women and girls, sex workers, men who have sex with men, and injecting drug users, tend to experience the harshest forms of HIV stigma, including violence and the refusal of health and other services. Thus, stigma tends to be most debilitating for people who are already socially excluded, most vulnerable to HIV, often subject to discriminatory laws, and frequently neglected in national AIDS responses.[16-22]

HIV stigma undermines prevention. People often avoid being associated with HIV, with devastating effects on prevention, care and treatment. Stigma can reduce the likelihood of people using condoms and accessing preventive services such as educational meetings and counseling.[39, 40] People who hold stigmatizing attitudes are also less likely to adopt preventive behaviors.[40, 41] One study among Chinese migrants found those holding stigmatizing beliefs were more likely to have multiple sexual partners, a commercial sex partner, and a sexually transmitted infection. Those with stigmatizing beliefs were also less likely to use condoms.[42]

Stigma can deter or delay testing and disclosure.[40, 43-48] In Botswana, a survey of HIV patients receiving antiretroviral therapy (ART) found that 40 percent had delayed getting tested for HIV, mostly due to stigma.[14] Stigmatizing beliefs, which perpetuate the notion that HIV only happens to others, also can reduce testing, as people are less likely to believe they are at risk.[40, 42] A study of truckers in Brazil found that men with more stigmatizing attitudes were less likely to have had an HIV test.[49]

Stigma often prevents disclosure of an HIV-positive status to partners, providers and family members, which in turn deters behaviors that can prevent further spread of HIV, such as condom use, or mitigate its impact, such as care seeking.[50-58] A review of 17 studies on disclosure found the main barriers to disclosure for women are fear of infidelity accusations, abandonment, discrimination and partner violence. Of women who disclosed, 3.5 percent to 14.6 percent reported experiencing a violent reaction from a partner.[53] Stigma also can delay disclosure. Only half of people living with HIV in a Tanzania study had disclosed their status to an intimate partner. Among those who had disclosed, the average time from knowing their status to disclosure was 2.5 years for men and 4 years for women.[24]

Stigma reduces the quality of care. As illustrated in Table 1, stigma deters use of and adversely affects quality of health services. People with HIV have been refused services, denied medicine, passed from provider to provider, tested for HIV or have had their sero-status disclosed without consent, and isolated unnecessarily.[13, 18, 20, 57] Groups such as sex workers, men who have sex with men and injecting drug users face additional barriers in accessing care. These include avoidance of care seeking due to fear of being "found out," discrimination by health workers, and, in some instances, of incarceration and having their property taken away.[29, 59-61]

Stigma can delay treatment and reduce survival. Delayed testing can lead to delayed diagnosis and treatment. People who begin ART in the earlier stages of HIV (e.g., stages two or three) have a longer life expectancy than people who wait until it is more advanced (e.g., stage four).[62-65] One study found a 94 percent increase in the risk of death among patients who did not start ART until stage four.[64]

Stigma impedes adherence to medication.[65-70] ART requires strict adherence for effectiveness, and adherence is the strongest determinant of patient survival.[63, 71] In South Africa, fear of stigma has led people to grind drugs into powder, which can result in inconsistent doses, and to avoid taking medicines in front of others.[72] Stigma also adversely affects mental health, and depression interferes with consistent drug use.[31, 73-76]

Table 1. Living with HIV Stigma and Discrimination: Selected Facts and Figures

Stigma can lead to a loss of livelihoods and resources.

- In Vietnam, 54 percent of people surveyed in the ward of Cai Khe said they would not buy food from a person suspected of living with HIV.[23]
- In Tanzania, 43 percent of a sample of people living with HIV lost access to a resource such as housing or employment.[24]
- Studies among employers in both China and Nigeria revealed strong reluctance to hire or retain employees with HIV.[25, 26]

Physical and verbal abuse is severe for already marginalized people.

- A study of street-based sex workers in Bangladesh found 60 percent reported being raped by police or other men in uniform in the previous year, most refusing to use condoms.[27]
- In the Dominican Republic, 53 percent of women living with HIV had experienced some form of physical violence after age 15.[28]
- In Senegal, a study of men who have sex with men found that 40 percent had experienced verbal abuse and 13 percent had experienced physical abuse by the police.[29]

HIV-related discrimination is common.

- A large household-based study in Kenya found 75 percent of HIV-positive respondents had experienced some form of discrimination, such as social rejection and segregation.[30]
- Slightly more than one-half of people living with HIV experienced discrimination in a China study of people living with HIV,[31] as had one-third of HIV-positive respondents in south India.[32]

Laws that justify stigma and discrimination are widespread.

- A recent estimate counts 31 countries with specific laws that criminalize HIV transmission or exposure and 49 low and middle-income countries with laws that prohibit sexual intercourse between people of the same sex, with penalties such as death, heavy labor and imprisonment.[21, 22, 33, 34]

Stigma reduces the use and quality of health services.

- In a Vietnam study, 60 percent of pregnant women who refused HIV testing cited fear and discrimination as the dominant reasons.[35]
- In Kenya, pregnant women avoided delivering at a health facility or deliberately destroyed their antenatal cards, which included their HIV status, for fear of discrimination by health providers.[36]
- A survey of more than 1,000 health care professionals working directly with HIV patients in four Nigerian states found 59 percent believed patients with HIV should be on a separate ward; 12 percent believed treatment of opportunistic infections wastes resources; and 43 percent observed others refusing hospital admission to a person with HIV.[37, 38]

Potential Impact of Stigma on Prevention of Mother-to-Child Transmission

How much can stigma reduction interventions affect outcomes such as infections prevented or deaths averted? For decision-makers, this is a key question because funding realities require prioritization of investments. Increasingly, this prioritization relies on data on the likely costs and effects of programs.[3]

Researchers have developed a model* to estimate the potential impacts of stigma on prevention of mother-to-child transmission (PMTCT) programs.[3]

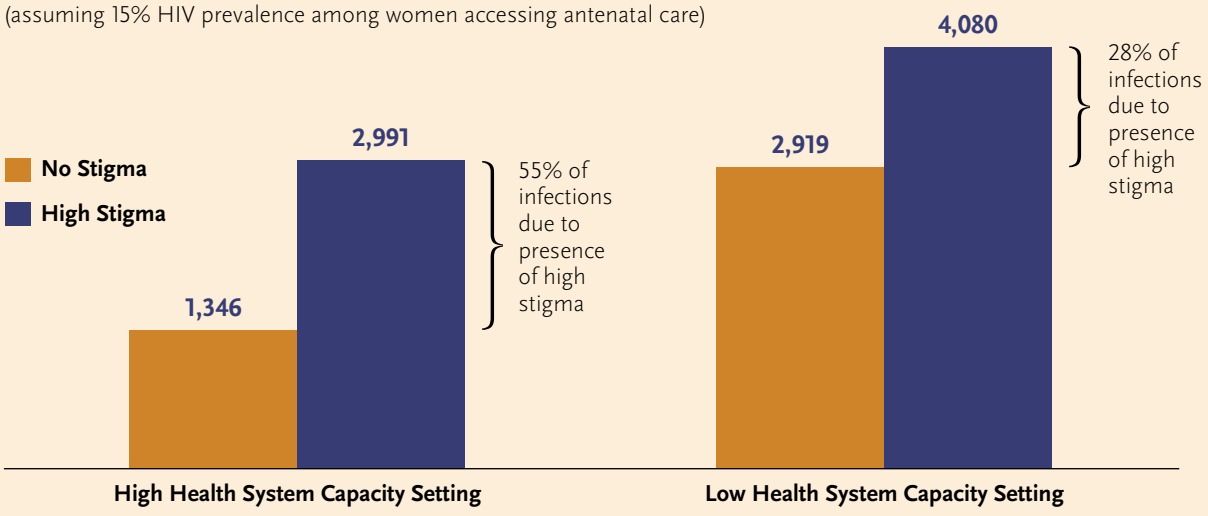
By adhering to recommended protocols, women could decrease the risk of HIV transmission to their child from about 35 percent to around 2 percent.[2] But program dropout and non-adherence are substantial.[77, 78] Stigma and discrimination are chief among the multiple factors that drive attrition at every stage.[79, 80] Among pregnant women, a perceived lack of confidentiality or fear of reprisal from a partner, family member or health care provider can hinder accepting or seeking an HIV test at an antenatal clinic.[36, 81-83] This fear is associated with nondisclosure of HIV status[18;84], and women who choose not to disclose are less likely to adhere to antiretroviral medication or to use prevention and treatment services.[36, 85, 86] In addition, mothers who do not use treatment are less likely to seek treatment for their infant.[79, 86] Finally, fear of stigma discourages mothers from adopting measures, such as exclusive breastfeeding for the first six months, that can lower transmission risk.[87, 88]

The model calculates how the multiple impacts of stigma combine to undermine PMTCT programs. Results suggest that stigma is a substantial factor in the transmission of HIV from mothers to their infants. In settings with both robust PMTCT services and high levels of stigma, up to 55 percent of mother-to-child HIV infections could be due to stigma.[3] Even where services are not as strong, one-third of transmission may be due to stigma. The most effective stigma reduction programs could potentially decrease transmission in high stigma settings by 16 to 29 percent.[3]

*The model draws upon the limited data available from the research literature to produce estimates. The results, while approximate, provide a sense of potential impacts.

Projected Number of Mother-to-Child Infections

(assuming 15% HIV prevalence among women accessing antenatal care)



(per 100,000 women accessing antenatal care services)

II. Mounting an Expanded Response to HIV Stigma and Discrimination

"I wish I had been exposed to this kind of training earlier on. I feel that [my parents] suffered more out of actions and attitudes from all of us in the family rather than they did from the virus."

– Community leader and stigma training participant, Tanzania[89]

Strong foundation exists for expanding stigma reduction efforts.

The fundamentals are in place for an expanded response to HIV stigma and discrimination. Research and field experience have identified the causes and consequences of stigma; promising approaches for reducing stigma among different groups, for challenging discrimination, and for promoting human rights[90, 91]; and practical tools and measurement strategies.

Tackling stigma requires addressing its immediate underlying causes. Research suggests these causes are consistent across different contexts[17, 92, 93] and include lack of awareness of stigma and its damaging effects; fear of acquiring HIV through everyday contact; and values linking people with HIV to behavior considered improper and immoral. These drivers of stigma can be addressed with any target group by creating awareness of what stigma is and the benefits of reducing it; fostering motivation for change; addressing fears and misconceptions about transmission of HIV; discussing "taboo" topics that are linked to and fuel HIV stigma and discrimination, such as gender, violence, sexuality and injecting drug use; and providing the skills to challenge stigma and to change behavior.[17, 24]

A participatory approach that fosters critical reflection about prevailing HIV-related attitudes, norms and behaviors is key to working with groups around stigma. This type of intervention has been used with groups ranging from teachers in Zambia to health care workers in India, Vietnam and Tanzania.[94-97] In Vietnam, a participatory approach catalyzed leaders of the Commission for Ideology and Culture of the Communist Party, which controls all media messaging, to create media guidelines for non-stigmatizing reporting on HIV and AIDS.[23]

A multifaceted approach tends to be more effective in reducing stigma (see Table 2). Combining strategies to address underlying norms that fuel stigma and discrimination is important. Education strategies to improve knowledge, for example, have limited effectiveness when used alone because they do not adequately address drivers such as harmful stereotypes.[15, 98]

Stigma reduction efforts following recommended practices have been quite effective in health care settings. Interventions in countries ranging from India, Ghana, Tanzania, Vietnam and China have decreased stigmatizing attitudes and discriminatory practices over time or in comparison to control groups.[13, 91, 99] Models for reducing stigma in public health services at a larger scale are emerging. In Ghana, the "High Impact Package" program addresses stigma and discrimination in the formal health sector as part of a broader effort to improve quality of care for people living with HIV and to scale up ART services. The program is rolling out in more than 30 hospitals.[100]

Advocacy can foster positive changes in laws and policies.

Legal and policy reform to better address the needs and rights of vulnerable groups can play an important role in reducing stigma and discrimination. Advocacy in Nepal persuaded the country's Supreme Court to direct the government to end discrimination against lesbian, bisexual and transgender people and to guarantee their equal rights.[101] In China, the China-U.K. HIV and AIDS

Table 2. Key Elements to Reduce Stigma and Discrimination

An effective large-scale response to HIV stigma and discrimination...	
Addresses key underlying drivers	Interventions need to address the root causes of stigma. These include lack of awareness of stigma and its damaging effects, fear of acquiring HIV through everyday contact, and values linking people with HIV to behavior considered improper and immoral.
Addresses multiple layers of stigma	Vulnerable groups typically experience stigma from multiple sources (e.g., drug use, sexuality, gender, sex work, HIV). Interventions that address HIV stigma alone may not improve outcomes for these groups.
Operates at multiple levels	Individual, family, community, organizational/institutional and government/legal
Engages multiple target groups, potential change agents, marginalized and vulnerable populations	These might include opinion leaders and influentials (e.g., politicians, faith-based leaders), front-line HIV responders (e.g., health care workers, NGO and community workers), people living with HIV and other stigmatized groups, communities, the media, private sector, schools, police and the judiciary.
Employs a range of strategies to: 1. Prevent and reduce stigma 2. Challenge discrimination in institutional settings 3. Promote and protect human rights through laws and policies	Successful approaches may involve a combination of: • Strengthening and building capacity of stigmatized individuals and groups (e.g., through skills-building, network building, counseling, training, income generation) • Involving people living with HIV and other stigmatized people (e.g. men who have sex with men and sex workers) • Participatory and interactive education • Behavior change communication such as media campaigns and edutainment programs • Institutional reform to address discrimination in workplaces, health care settings, schools and other institutions • Policy dialogue and legal and policy reform together with enforcement and mechanisms for redressing rights abuses especially at local levels • Equal treatment of people living with HIV in the provision of services, care and treatment

Adapted from: Understanding HIV Stigma and Its Impact: Mounting a Stronger Response, *DFID, 2007*

Prevention and Care project helped transform the attitudes of officials toward vulnerable groups, which led to the expansion of needle exchange and other harm reduction services.[90]

In improving legal protections, groups of people living with HIV that work with lawyers' organizations tend to be more successful.[102, 103] Additionally, the power of anti-stigma interventions is often magnified in settings with enforceable laws that support the rights of people living with HIV. South Africa's Treatment Action Campaign has drawn upon a supportive legal framework to advance the rights of people living with HIV and to secure greater drug availability.[103, 104]

Indicators are available to monitor progress and evaluate effectiveness.

Measuring progress and effectiveness helps improve programs and convince policy makers of the value of stigma reduction interventions. Efforts are underway to standardize and consolidate indicators that have been tested in the field, facilitating global tracking of stigma and comparative research.[105] The People Living with HIV Index* measures stigma as directly experienced by people living with HIV. The index helps strengthen the research skills, self-efficacy and leadership of people living with HIV because they design and implement it. The Index, rolling out in more than 12 countries, will provide useful data for programming and advocacy.[106]

*www.stigmaindex.org

III. Next Steps: Agenda for Moving Forward

"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, former executive director of UNAIDS[107]

The intensity and scale of response to stigma can and must be expanded. The building blocks are in place. Promising tools and approaches are available. Practitioners know how to inspire change in communities, health care settings and workplaces. There is a core agenda for legal reform to establish better protections for people living with HIV, guarantee their human rights and banish laws that discriminate against people living with HIV. Research has yielded solid indicators for monitoring progress and evaluating results in stigma-reduction efforts. New evidence further strengthens the case for action by quantifying how reducing stigma could result in fewer HIV infections. Networks and alliances are in place worldwide to help take action items forward. The following agenda* for donors, researchers, programmers and advocates outlines action items for achieving greater scale.[108]

Research

Build the evidence base on the value of stigma reduction efforts.

Quantifying how stigma reduction interventions increase uptake of specific services and protective behaviors is critical to unlocking greater resources from the largest funders. Few stigma reduction programs have been evaluated and little if any cost and cost-effectiveness data are available.[16, 109] Further modeling analyses can help make the impact of stigma on AIDS programming more concrete. Without these data, decision-makers are hard-pressed to factor stigma reduction into national plans.

Programs

Standardize approaches and guidance to support scale-up efforts.

Standardized guidance on how to address stigma and discrimination is critical for larger-scale planning and roll-out. This type of guidance will require consensus on what works, how to monitor progress and costs. It also entails consolidating and standardizing definitions, tools and indicators.

Increase testing and translation of intervention tools.

New tested tools are needed to foster stronger engagement of gatekeepers such as religious leaders and politicians. Additionally, tools are needed to address the needs of "multi-marginalized" groups such as sex workers. Existing tools should be more widely translated for broader use.

*Recommendations are drawn from a study assessing barriers and facilitators for scale and are based on reviews of the research literature, interviews with key informants, and an online survey of practitioners.

Mobilize support for "best practice" field programming.

Stronger support is needed for programming that:

- Addresses deep-seated drivers of stigma and discrimination;
- Has funding for 3 to 5 years, providing time to take root;
- Is tailored to the context;
- Involves people living with HIV and other vulnerable groups in all phases;
- Employs multiple strategies simultaneously; and
- Incorporates strong formative research for program development, as well as monitoring and evaluation.

Prioritize the health sector for expansion and institutionalization of stigma reduction.

With tested tools and a promising body of evidence, stigma reduction efforts are poised to be taken to scale in the health sector. But it will be important to shift from occasional trainings or ad hoc activities to a more long-term, systematic approach focused on institutionalizing programming. This means sustained efforts to embed stigma reduction in national regulations, medical education and in-service training.

Communications and Advocacy

Better market and communicate existing work to drive expansion.

This entails more joint action by researchers, programmers, advocates, people living with HIV, and other affected groups, and a network for communicating information more widely. Important agenda items include designing and implementing a global communications strategy, developing a compendium on what works to reduce stigma, consolidating existing measures and measurement tools, and initiating a coordinated advocacy campaign.

Conduct stronger advocacy at multiple levels.

Advocacy needs to include more strategic engagement with donors and policy makers, participation in meetings and consultations to provide inputs into plans and proposals, wider dissemination of key research findings on stigma, and coordination of networks and coalitions for joint action.

Increase collaboration with human rights groups to counter discriminatory laws and policies.

Working with human rights groups, who have expertise with laws, policies, and human rights instruments, is critical. Minimal legal standards to advance rights and reduce HIV vulnerability include: decriminalize HIV status, transmission, and exposure; decriminalize sex work; decriminalize prohibitions on same sex relationships and sexual practices; and guarantee equal rights of people living with HIV and AIDS.[110]

Capacity strengthening

Equip networks of people living with HIV and other vulnerable groups to intensify stigma-reduction efforts.

Networks of people living with HIV and other vulnerable groups are often called upon to help design and lead efforts against stigma and discrimination. But many of these groups are underfunded and have multiple capacity needs, ranging from management to fundraising.

Expand training to drive expansion.

A scaled-up response to stigma will require more trained personnel. Key training areas include evidence-based advocacy, program evaluation, and implementation of stigma-reduction interventions. Additionally, training in stigma and discrimination is important within AIDS organizations to reduce stigma among staff and in services.

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ICRW International Center for Research on Women
where insight and action connect

Headquarters

1120 20th St. N.W.
Suite 500 North
Washington, D.C. 20036 USA
www.icrw.org
Phone: (202) 797-0007
Fax: (202) 797-0020
E-mail: info@icrw.org

Asia Regional Office

C – 139 Defence Colony
New Delhi – 110024 India
www.icrw.org/asia
Phone: 91-11-2465-4216
Fax: 91-11-2463-5142
E-mail: info.india@icrw.org

Keppel Street
London WC1E 7HT, United Kingdom
www.lshtm.ac.uk
Phone: +44 (0) 20 7636 8636