WORKING PAPER

Roadmap Toward an Expanded Response to HIV Stigma and Discrimination

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Executive Summary

Evidence from diverse countries suggests that expanding the response to stigma and discrimination could improve the duration and quality of life of people living with HIV, and optimize investments in HIV prevention, care and treatment. Yet a significant gap exists between the need for an expanded response and the scale and intensity of actions to date. To help bridge that gap, this paper documents and analyzes the facilitators that exist to support an expanded response and the barriers that need to be addressed if efforts to reduce stigma and discrimination are to be scaled up.

The paper draws primarily on a rapid scan of the field conducted from May to August 2009 consisting of in-depth interviews with 21 key informants representing networks of people living with HIV, the United Nations and donor agencies, academia, and nongovernmental organizations, and an online survey completed by 68 practitioners working on stigma reduction. Two other sources of data are a review of the literature on HIV stigma and discrimination and an international meeting held in Washington, D.C., in November 2008 to prioritize steps to galvanize global action to reduce HIV stigma and discrimination.

The facilitators and barriers cluster around four areas: evidence base, programming, communications and advocacy, and capacity strengthening. Although there is growing evidence on effective stigma reduction approaches, there is little cost-effectiveness data to help policy-makers prioritize stigma reduction in national plans. While there are tested tools for community and health care settings, their existence is not widely communicated to the field. Moreover, programs lack tools for addressing stigma experienced by multimarginalized groups, such as sex workers and injecting drug users. Although there have been legal reform successes, such as in Nepal and South Africa, greater advocacy is needed to counter discriminatory laws. Despite successful efforts led by networks of people living with HIV, there is a need to strengthen their capacity in leadership, evaluation, programming and evidence-based advocacy so that these groups can take on a larger role.

The findings from this analysis provide strategic direction for expanding the response to HIV stigma and discrimination. To move the field forward, donors, researchers, programmers and advocates need to work together to build the evidence base, promote tools and approaches and develop new ones as needed, mobilize actors to counter discriminatory laws and policies, and build capacity among key groups.

Introduction

Even where crucial services for HIV and AIDS are widely available, uptake is often lower than desired. Program managers in countries as varied as India, South Africa and Mexico have discovered that people living in fear and denial are less likely to adopt preventive behavior, come in for testing, disclose their serostatus to partners, and access care, treatment, and support. They have seen the lengths to which people will go to distance themselves from HIV, such as not seeking care until extremely ill, grinding pills into powder to conceal medication from loved ones, and traveling far from home and local gossip to visit health providers.

More than 20 years have elapsed since Jonathan Mann, the first head of the World Health Organization's Global Programme on AIDS, predicted the epidemic would be characterized by stigma, discrimination and denial, all of which would become as central as the illness itself.[1;2] Research has confirmed that stigma is globally prevalent, widely pervasive and highly damaging.[1;3-9] Yet a significant gap exists between the need for an expanded response to stigma and discrimination and the scale and intensity of actions to date, most of which are small-scale or in a pilot phase. Thus, an important question is how to accelerate progress and close the gap. This paper responds to that question by documenting and analyzing the facilitators that exist to support an expanded response and the barriers that need to be addressed if efforts to reduce stigma and discrimination are to be scaled up.

Sources and Methods

In charting a way forward, this paper draws primarily on a rapid scan of the field conducted from May to August 2009 consisting of in-depth interviews with 21 key informants and an online survey completed by 68 respondents. The key informants were selected purposively to represent a variety of perspectives, including networks of people living with HIV, the United Nations and donor agencies, academia, and nongovernmental organizations (NGOs). The informants were geographically diverse, being based in Africa, Asia, Europe, Latin America and the Caribbean, and North America.

The online survey complemented the key informant interviews by capturing a broader range of opinions from practitioners. The survey was disseminated through existing networks and to individuals involved in efforts to reduce HIV stigma and discrimination. Thus, the sample was not random or scientifically selected to represent the larger community working on HIV stigma and discrimination. In terms of survey respondents, nearly 60 percent work for NGOs or community-based organizations. Nine out of 10 reported being involved in efforts to reduce HIV stigma. The majority of respondents do most of their work in Sub-Saharan Africa or the Asia/Pacific region.

Additionally, the scan is supplemented by these two sources:

(1) A review of the literature on HIV stigma and discrimination, including review papers recently produced by the authors for the Department for International Development (DFID) and the Joint United Nations Programme on HIV/AIDS (UNAIDS).[10;11]

(2) An international meeting held in Washington, D.C., in November 2008 to prioritize steps to galvanize global action to reduce HIV stigma and discrimination. Convened by the MAC AIDS Fund and the International Center for Research on Women, the meeting brought together 58 experts from the program, research, policy, advocacy and donor sectors.[12]

Key Findings

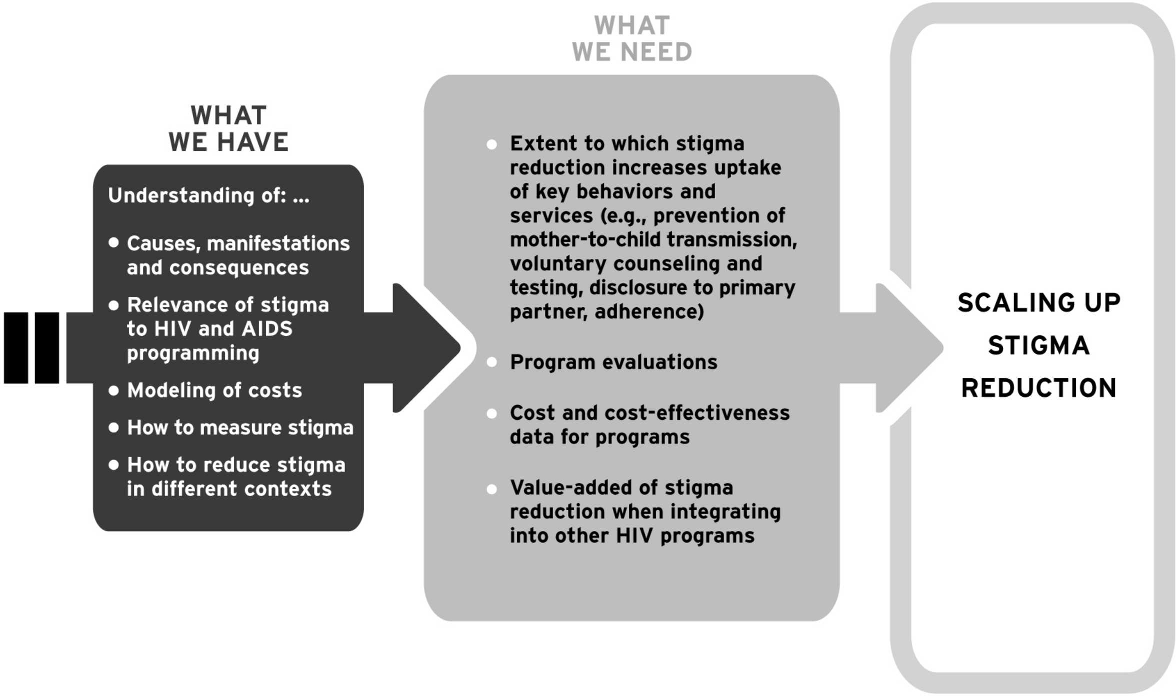
The facilitators and barriers identified from the literature, the international meeting and the rapid scan cluster around four areas: (1) the evidence base; (2) programming; (3) communications and advocacy; and (4) capacity strengthening.

Evidence Base

Facilitators in this area include a growing body of research that has sharpened understanding of the drivers and dimensions of stigma, as well as the entry points for intervention.[1;5;7-9;13-16] Evidence from programs in countries such as India, Tanzania and Vietnam indicates stigma reduction efforts can bring about powerful changes in attitudes and behaviors.[17-20] The majority of respondents from the rapid scan agree there is strong evidence for how to reduce stigma in health facilities and among providers.

Despite this progress, important gaps in the evidence base impede making the case for scaling up stigma reduction (see Figure 1 for evidence base facilitators and gaps). A disparity persists between the evidence desired by the largest AIDS funders and the data available on stigma

FIGURE 1: Evidence Base: Facilitators and Gaps for Stigma Reduction Scale-Up



and discrimination. Although donors may be sympathetic to human rights imperatives for action, such imperatives are typically not sufficient to unlock major resources for scale on the order of national programming.* As one rapid scan respondent noted, "Everyone is well intentioned, but at the end of the day everyone reverts to outcomes." Highlighted in the following paragraphs are the principle research recommendations for bridging the gaps in the evidence base in order to make a stronger case for going to scale.

- ***Demonstrate the attributable difference of stigma reduction on prevention, care and treatment outcomes***

Overall, scan respondents indicated that the largest AIDS funders are looking for more rigorous and quantifiable evidence of how stigma and discrimination efforts advance public health goals. A number of studies have documented that stigma and discrimination deter people from testing and treatment. But an important knowledge gap is the extent to which decreasing stigma increases uptake of services and healthier behaviors.[21] A key question is how stigma reduction accelerates progress toward national targets for prevention, care, treatment and support.

Filling this evidence gap requires studies that assess how reducing stigma and discrimination affects key outcomes. For example, a study could look at how stigma reduction intervention increases the number of people who come in for counseling and testing or how it increases disclosure to intimate partners or increases adherence to safer infant-feeding practices.

A related knowledge gap concerns the extent to which increased access to testing and treatment reduces stigma and discrimination.[21] Some respondents expressed concern about the perception, particularly among large funders, that treatment rollout by itself will decrease stigma and discrimination. Evidence to date is mixed but on balance suggests treatment alone may not be sufficient. Although some studies indicate expanded antiretroviral therapy (ART) services reduce stigma,[21-24] others suggest otherwise. One recent study in South Africa, for instance, found that stigma increased among young adults from 2003 to 2006 despite antiretroviral rollout and strong HIV prevention messaging targeting this group.[25] Researchers conducting a qualitative study in rural Tanzania found new types of stigma connected with

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* Recommendations may vary by types of scale being considered. One type includes scale on the order of national or regional programming. The major avenues supporting large-scale efforts include country governments; DFID; The Global Fund to Fight AIDS, Tuberculosis, and Malaria; and the President's Emergency Plan for AIDS Relief. Another type of scale concerns expansion of existing efforts. This may mean increasing a promising project from three districts to 15. Expanding current work can help build the case for national scale. But in some cases the identified needs for large scale are distinct from project expansion. These distinctions, where relevant, are noted in the text.

ART scale-up, including heightened fear and blame as community leaders perceived ART users regaining health, having sexual relations and spreading "disease."[26] An important point is that stigma has persisted in high-income countries despite widely available therapy.[27] As one scan respondent living with HIV noted, "Stigma has not gone away in the U.K. even though there is treatment."

- ***Collect data on the effectiveness and cost of interventions***

Another major barrier to progress is a widespread lack of evaluation and cost data. This gap, identified by scan respondents and research reviews,[21;27] poses multiple challenges to expansion. Limited evaluation data, for instance, complicate efforts to establish consensus on how to address stigma and discrimination. This situation impedes the ability of advocates to convince decision makers that programs work. A number of respondents pointed to the challenges of costing a national plan for stigma reduction without any cost data.

The demand for cost-effectiveness information, particularly in a context of constrained resources, is increasing. For instance, the Commission on AIDS in Asia, noting that available resources amounted to US$1.2 billion out of $6.4 billion needed for regional scale-up in 2007, recommended countries fund only the most cost-effective interventions. To that end, the commission classified interventions into four categories: low cost/high impact, high cost/high impact, high cost/low impact, and low cost/low impact. The classification was based on research examining the relative costs of interventions in light of estimates regarding the number of infections prevented, deaths averted and income losses avoided. With frameworks such as these, it is difficult for planners to factor stigma and discrimination interventions into their national responses without relevant cost and evaluation data.[28]

Programming

There is a rich programming base to build upon to facilitate an expanded response. Practitioners have fielded tools for use in settings ranging from communities to health care institutions. Nearly six in 10 survey respondents agree with the statement, "We have strong training materials and tools for reducing stigma." One important resource is the toolkit *Understanding and Challenging HIV Stigma*.[29] With a customizable menu of options and its availability in several languages, the toolkit is being used with a wide range of groups. Other existing tools are more focused on specific audiences. *Reducing Stigma and Discrimination Related to HIV and AIDS: Training for Health Care* addresses providers, while the *PLHA-Friendly Achievement Checklist* helps managers assess and address stigma within health care institutions.[30;31] The *Called to Care* booklet series is for church leaders.[32] These are just some examples.

Practitioners can also draw upon lessons for engaging influential people and mobilizing communities. Although influential people are often seen as barriers to stigma reduction, experiences from varied settings suggest that, with support and effort, they can become important allies. In Vietnam, a stigma reduction project achieved the buy-in of top government officials, who issued new anti-stigma guidelines for the country's information, education and communication efforts.[17]

Another programming strength is proven leadership from affected communities: 83 percent of survey respondents agreed with the statement, "We have strong examples of how people living with HIV can shape and/or lead responses against stigma." Additionally, progress is being made in measurement, an area that has an impact on programming. Efforts are under way to standardize and consolidate indicators, which should strengthen monitoring and evaluation, thus contributing to improved programs. These efforts include stakeholder meetings on measurement that aim to establish a harmonized set of global-level stigma indicators approved by the UNAIDS Monitoring and Evaluation Reference Group.[†] Innovative activities, such as the People Living with HIV Stigma Index initiative (see Box 1), provide models for empowering people living with HIV, measuring stigma and discrimination as experienced by affected communities, and using evidence to improve programs.

Despite these gains, a number of barriers inhibit expansion (see Figure 2 for a depiction of the programming facilitators and gaps). A lack of standardized guidance on programming is a key gap. As one scan respondent noted, "There is a bias toward clear, measurable, easy-to-roll-out efforts. . . . We need an easy guide on how to do programming." Such guidance might help change perceptions identified as barriers to expansion — that stigma reduction efforts are labor-intensive, costly, and effective only when used in small-group settings. But to develop effective guidance, there needs to be consensus on what works and how to operationalize programming, which is lacking.

New tools are also needed to strengthen the programmatic toolbox. Among online survey respondents, a top recommendation to donors was the need to "fund the development,

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[†] An international stakeholder meeting took place in November 2009 to facilitate discussion and consensus on stigma measurement. The meeting was convened by the Global Network of People Living with HIV, the International Center for Research on Women, the International Planned Parenthood Federation, Johns Hopkins Bloomberg School of Public Health and UNAIDS.

Box 1. The People Living with HIV Stigma Index Initiative

In 2004, a multi-organization partnership initiated the People Living with HIV Stigma Index (www.stigmaindex.org). The index, created and implemented by people living with HIV, uniquely measures stigma and discrimination as directly experienced by this group. The implementation process is specifically designed to strengthen the research skills, self-efficacy and leadership of people living with HIV.

The People Living with HIV Stigma Index is being rolled out in many countries, primarily through the lead of country networks of people living with HIV. Network members are trained to field a questionnaire that explores the following issues:

- Experiences of stigma and discrimination and their causes
- Access to work and services
- Internal stigma
- Rights, laws and policies
- Effecting change
- HIV testing, disclosure and confidentiality, and treatment
- Having children
- Problems and challenges

Once the data are collected and analyzed, the next step is converting the results into action. This involves disseminating the data; creating, implementing and monitoring action plans around the findings; and conducting multiple rounds of the index to detect trends and progress. The founding international partners are the Global Network of People Living with HIV, the International Community of Women Living with HIV and AIDS. the International Planned Parenthood Federation and UNAIDS.

testing and translation of more tools for use on the ground." This would include tools that support more effective work with opinion leaders and gatekeepers, and that address the needs of marginalized groups, such as intravenous drug users and sex workers, who face multiple intersecting stigmas. The lack of a globally agreed upon standard set of stigma indicators also impedes expanding stigma reduction programming.

Respondents proposed a number of ideas for enhancing and expanding programming. Common themes include the need for more investment in "best practice" programming, for greater involvement of people living with HIV and other stigmatized groups, and for more sustained funding. Particular tensions surfaced around shorter-term versus longer-term efforts, especially regarding communications campaigns. Key recommendations are discussed in more detail in the following paragraphs.

- ***Produce standardized guidance on how to address stigma and discrimination***

Rapid scan respondents widely cited the need to develop more operational and normative guidance on stigma reduction. As one respondent noted, "At the policy and strategic planning level . . . there needs to be planning guiding documents." Another respondent called for "programmatic guidance that is easy for people to take up and put into funding," and noted the need to "break down programs into 5 or 6 elements so people can see how to do it and can put these programs into funding proposals for The Global Fund."

Recent guidance publications on issues that are relevant to stigma reduction are important advances. For example, a multi-organization partnership has produced guidance on supporting the sexual and reproductive health rights of people living with HIV.[33] The report covers topics including advocacy, health systems, and policy and legal reform. A recently published document, *Toolkit: Scaling Up HIV-Related Legal Services*, provides operational direction for establishing, strengthening or expanding programming in legal services. Produced by the International Development Law Organization, UNAIDS and the United Nations Development Programme, it features a glossary and definition of HIV-related legal services and sections on overarching principles, service models, designing locally appropriate legal services, capacity building, monitoring and evaluation, and resource mobilization. The appendices include examples of training material, a funding proposal, a monitoring and evaluation framework, and information on funders.[34]

FIGURE 2: Programming: Facilitators and Gaps for Stigma Reduction Scale-Up

But guidance more specific to stigma reduction is still needed, and this will likely entail a collective effort. Guidance is often produced at the initiative of U.N. entities or interagency working groups. Inputs to guidance are often broad, sought through global and regional consultations, policy meetings, working group recommendations and other activities.

Guidance needed for stigma reduction would define basic terminology and cover topics such as overarching principles, goals and targets, policy issues, priority strategies and actions, and monitoring and evaluation. Additionally, guidance needs to address different types of stigma reduction programming efforts. These include stand-alone programming, programming added on to existing efforts and programming that is fully integrated into existing efforts. This would mean systematically addressing questions such as how to assess what type of programming is needed; how to design and implement such efforts; unit costs; and needed expertise. The basis for integrated guidance may be emerging, although it is not yet documented. Some scan respondents mentioned that they are already incorporating stigma reduction efforts into existing prevention, care and treatment programming.

Guidance for the health sector is particularly important. In general, many respondents identified stigma reduction in health care as possessing "readiness" for scale, with a reasonable evidence base, existing training material and tested tools. Research confirms that the need remains great, as ample evidence reveals discrimination against people living with HIV and other stigmatized groups in seeking and obtaining health care.[4;13;14;35-40]

Many respondents identified government action on stigma in health services as a top priority. Among survey respondents, for instance, the second most common recommendation for government was to "support stigma reduction training for all health providers." The top recommendation was to "integrate stigma reduction into all prevention, care, and treatment efforts," which has enormous implications for health services. At the same time, little if any systematized guidance exists for integrating stigma reduction across health services. A promising development, however, is the recent formation of an ad hoc international group to develop a standardized curriculum on HIV stigma for health workers.[‡] This effort, especially with the participation of WHO, is an important step toward providing program guidance through systematizing and disseminating training curriculum standards.

[‡] This ad hoc group was formed at a September 2009 meeting to discuss the formation of a global stigma knowledge network. During the meeting, several participants who had previously been working independently on stigma reduction in health care facilities agreed to work together on a standardized curriculum for health providers on stigma reduction. This group then approached WHO, which agreed to join the group and has commissioned a rapid assessment of existing tools as background to inform the curriculum development process.

- ***Create new tools for multimarginalized groups and opinion leaders***

Researchers have shown that multimarginalized groups tend to experience the most severe forms of stigma and discrimination. Such groups include girls and women, injecting drug users, sex workers, men who have sex with men, migrants, prisoners and others. Evidence suggests that the stigma these groups already experience in association with their gender, sexuality, race, drug use and other factors magnifies the effects of HIV-related stigma.[6;8;9;41-47] Thus interventions need to address multiple sources of stigma to better reach and serve already stigmatized groups.[48] These groups are also prone to self-stigma, whereby society's negative attitudes are internalized, which complicates health care seeking and is associated with depression, shame and isolation.[49] Thus, interventions need to address multiple sources of stigma to better reach and serve already stigmatized groups.[48] Yet relatively little is known about effective program approaches and tools for addressing intersecting or layered stigmas.[43;50-54]

Expanding stigma reduction efforts will entail generating more support and engagement from opinion leaders and decision makers, especially religious leaders and policy-makers. Religious organizations could play a key role in expanding stigma reduction efforts and increasing the health and well-being of people living with HIV. Recent research highlights the need to work with religious leaders to combat stigma. One study in Tanzania, for example, found a strong association between some religious beliefs and support for shame-related HIV stigma.[55] Another study in Tanzania found that whereas prayer and religious faith may strengthen after an HIV diagnosis, even supporting adherence to ART, few respondents reported disclosing their status to their religious organizations because of fear of stigma. Additionally, while respondents noted that churches and mosques commonly disseminated HIV prevention messages, messages about living with HIV were rare.[56]

In general, the need to engage a wide variety of opinion leaders surfaced as a priority. Nearly seven in 10 online survey respondents felt that sufficient political and other leadership does not exist for a substantially expanded response. Respondents emphasized the need for more support from decision makers at every level. At the same time, few stigma-related tools and materials are tailored for use with decision makers.

Scan respondents also indicated that tools that foster a strategic and systematized approach to working with decision makers could accelerate progress. An important first step is defining gatekeepers and influential individuals. A working group on sex, rights and the law recommends that programs identify "influential power brokers and gatekeepers: those who set and monitor norms that increase vulnerability and or those with necessary connections for helping affected communities achieve greater resilience."[57] Another key action is to forge bonds with organizations with the resources and connections to effectively address obstacles to change.[57]

- ***Establish a core set of stigma and discrimination indicators***

Although researchers have made strides in measuring stigma, there is still little standardization in this area.[27;58] The need for a globally agreed upon standard set of stigma indicators is critical to expanding stigma reduction programming. One scan respondent, discussing how resources are allocated in the global HIV response, observed, "The only things that matter are things that you can count."

Ideally, a core set of stigma and discrimination indicators would become part of how countries and the international community monitor progress against the epidemic. These would enable tracking the success of stigma reduction efforts, any unintended consequences, and changes in stigma across time and settings. They would also enhance accountability, foster greater investment and enhance shared understanding of progress. In terms of achieving scale, incorporating indicators into country plans and frameworks used by the United Nations General Assembly Special Session, the President's Emergency Plan for AIDS Relief and The Global Fund would be important steps.

The past decade has seen an increase in the number of tested and validated scales for measuring HIV stigma among a range of target groups, including the general population, health providers and people living with HIV.[59] However, while most of these efforts measure the same underlying key constructs of stigma, there are often variations in the number, wording and combination of items tested, which limits comparability. Further work is needed in standardizing indicators for different groups.

Few efforts have measured stigma at the structural or institutional levels. Little is known, for example, about the prevalence and determinants of stigma by institutional context. Given the pervasiveness of stigma, and the importance of intervening at multiple levels, this is a major need. Without measures of institutional stigma, intervening at this level will be challenging.[27] Another key gap is that few measures get at the dynamics of multiple, intersecting stigmas such as those experienced by men who have sex with men, intravenous drug users and sex workers.

In addition, at the global level, a need exists for tested and validated measures that meet programming needs. Although some indicators are used globally, such as those from the

Demographic and Health Surveys, they are insufficient as they fail to capture the causes of stigma and other key information. Programs also require indicators that meet both short-term project needs for monitoring and the annual reporting requirements of large funders. Further, program indicators are needed that can be rolled up to the national and global levels to meet reporting requirements at those levels.

The need for building consensus for a global set of indicators has spurred action in this area. As mentioned earlier, a multistakeholder meeting held in November 2009 brought together a diverse group, including people living with HIV, academic measurement experts, U.N. and Office of the Global AIDS Coordinator agency representatives, and programmers to discuss the current state of the field, agree on key domains or areas of stigma that require measurement, and plan next steps for moving toward the ultimate goal of a tested and validated set of global indicators.

- ***Invest in "best practice" programming that addresses the drivers of stigma***

Scan respondents indicated the need for greater investment in effective approaches, based on the limited data available. A number of respondents suggested that existing funds should be allocated more efficiently, away from one-off conferences or "superficial" communication campaigns and toward more sustained work at the community level or within institutions to address the drivers of stigma. Research conducted across varied settings has identified three key actionable drivers of stigma: a lack of awareness and knowledge of stigma and discrimination; fear of acquiring HIV through everyday contact with infected people; and values linking people with HIV with behavior considered improper and immoral, thus justifying discrimination.[5;14;17] One respondent advised, "Programs should identify sources of stigma and discrimination in the targeted communities and develop costed strategies, messages, activities and programs to effectively deal with these sources of stigma and discrimination."

The research tends to confirm these recommendations made by respondents.[10;58] Characteristics identified with more effective programming include efforts that:

- address deep-seated drivers of stigma and discrimination;
- have support for three to five years, providing time to take root;
- are tailored to context;
- involve people living with HIV and other stigmatized groups in design, implementation and monitoring; and
- employ multiple strategies at one time to achieve change.

Given the pervasiveness of stigma, a large-scale response would need to intervene at different levels, including with families, communities, institutions such as health care facilities and places of employment, the media, and policies, laws, and legislation.[60] A number of respondents mentioned that more work is needed in addressing stigma and discrimination within institutional settings such as workplaces.

- ***Balance the use of shorter-term strategies with longer-term efforts to change norms and values***

Among respondents, particular tensions emerged in connection with shorter-term versus longer-term efforts. This played out strongly in discussions about mass media campaigns, which, as a review article notes, are "relatively understudied but widely implemented."[27] Some scan respondents expressed concern about disproportionate funds directed toward short-lived campaigns, many of which are unevaluated. Others proposed more balance, as one survey respondent noted, "In campaigns and communications, there is a balance to be struck between high-profile campaigns that make a splash but are short-lived and the longer-term ongoing communications that foster deeper changes in norms, values, and culture."

The evidence available on mass communications and HIV and AIDS varies. One review of 24 studies found modest impacts of mass communication programs on transmission knowledge and risk behavior (although none looked at HIV stigma specifically), while a study in Botswana found that viewers of the soap opera *The Bold and the Beautiful* expressed significantly lower levels of HIV stigma compared with nonviewers.[27] Scan respondent opinions also varied. Some noted the "inability of communication campaigns to successfully address myths and misconceptions." Others maintained that communications efforts are key to addressing the harmful norms that help drive stigma.

What may be at issue is how campaigns are designed and implemented. As with other programs, these efforts should be based on formative research, involve affected communities in all phases, and feature solid monitoring and evaluation to assess progress and results. Additionally, such efforts should be part of a package of intervention activities. Research from Vietnam, for example, has pointed to a "dose-response" effect in results: increased exposure to more and varied intervention activities, including communication campaigns, translated into greater reductions in stigma.[17]

The tensions surrounding short- versus long-term efforts also surfaced in relation to funding. A number of rapid scan respondents emphasized the need for ongoing support, pointing out that often funding was available only for a year or a short period of time, which meant a scattershot or one-off approach. Many pointed to the difficulty of challenging discriminatory beliefs in one or two meetings. Some respondents noted that shorter-term efforts, if done well, can transform individuals, but changing the structures around individuals takes more time. Sustained effort is important to training programs, especially those working with public sector personnel, where high turnover or formal rotation is common.

- ***Support increased involvement of people living with HIV in combating stigma***

There was strong consensus among scan respondents for greater involvement of people living with HIV in shaping or leading responses against stigma and discrimination. Despite the GIPA (greater involvement of people living with HIV) principle, many respondents maintained that people living with HIV were still inadequately involved in stigma reduction. Among survey respondents, one of the top recommendations for donors was to "fund greater involvement of people living with HIV or affected by HIV in stigma reduction efforts." On an encouraging note, more than eight in 10 survey respondents agreed with the statement, "We have strong examples of how people living with HIV can shape and/or lead responses against stigma."

- ***Institutionalize stigma reduction in the health sector***

Many respondents pointed to the health sector as a priority area for expansion, given the concrete benefits to people living with HIV and the promising work in this area. Numerous studies document that health providers discriminate against people who are HIV-positive[3;19;38;41;60;61] or whom they suspect have the virus. People may be refused services, denied medicines, passed from provider to provider, tested for HIV or have their serostatus disclosed without consent, and isolated unnecessarily. At the same time, a growing body of evidence demonstrates stigma reduction interventions in health care settings can be quite effective. Efforts in settings as varied as India, Ghana, Tanzania, Vietnam and China have generated improvements in stigmatizing attitudes and discriminatory practices over time or in comparison with control groups.[19;58;62]

As for next steps, scan respondents emphasized the need to shift from occasional trainings or ad hoc activities to a more strategic approach centered on institutionalizing programming. This is also a more sustainable approach, ensuring programs are part of institutions instead of reliant on individuals, many of whom change jobs or rotate positions. Among online survey respondents, for instance, a top recommendation for donors was to "fund efforts to institutionalize stigma reduction into the training and education of health providers."

Box 2. Ghana's Effort to Address Stigma and Discrimination in the Formal Health Sector

In Ghana, addressing stigma and discrimination in the formal health sector is part of a broader effort to improve the quality of care for people living with HIV and to support the scale-up of ART services. The High Impact Package (HIP), a collaboration among the National AIDS and STI Control Programme, EngenderHealth, and the Academy for Educational Development, is rolling out a package of care in more than 30 hospitals. The program addresses both the supply and demand sides of the care and treatment equation. It draws upon an existing quality improvement tool for providers, COPE, and applies it to ART services. Participatory training raises providers' awareness about stigma and their own attitudes and behaviors, and offers information to alleviate fears about HIV infection. At the same time, the program includes dialogue with communities of people living with HIV to discuss their needs and strengthen their links with providers and facilities.

HIP is one of the few efforts to achieve some scale, covering facilities serving the majority of patients living with HIV in Ghana. Program rollout prioritized facilities based on the highest patient load of people living with HIV. HIP has not yet been formally evaluated, but lessons are being documented. In terms of achieving national coverage at all facilities, challenges ahead include the sheer numbers of people to be sensitized and trained.

Some promising work is taking place in this area, such as the effort to establish a standardized curriculum for health workers mentioned earlier, an initiative with the Vietnam Ministry of Health to strengthen universal precautions in national hospital regulations, and the rollout of a package of services to address HIV stigma in Ghana's hospitals (see Box 2). But rapid scan respondents expressed the need for additional work in this area, providing a number of suggestions. Programming could be incorporated into nursing colleges, medical schools, continuing medical education and refresher HIV training. Anti-discriminatory measures could be folded into standard operating policies and procedures within facilities. Institutions could require certification and training for personnel, which could be framed as "diversity training" to increase acceptance among stakeholders.

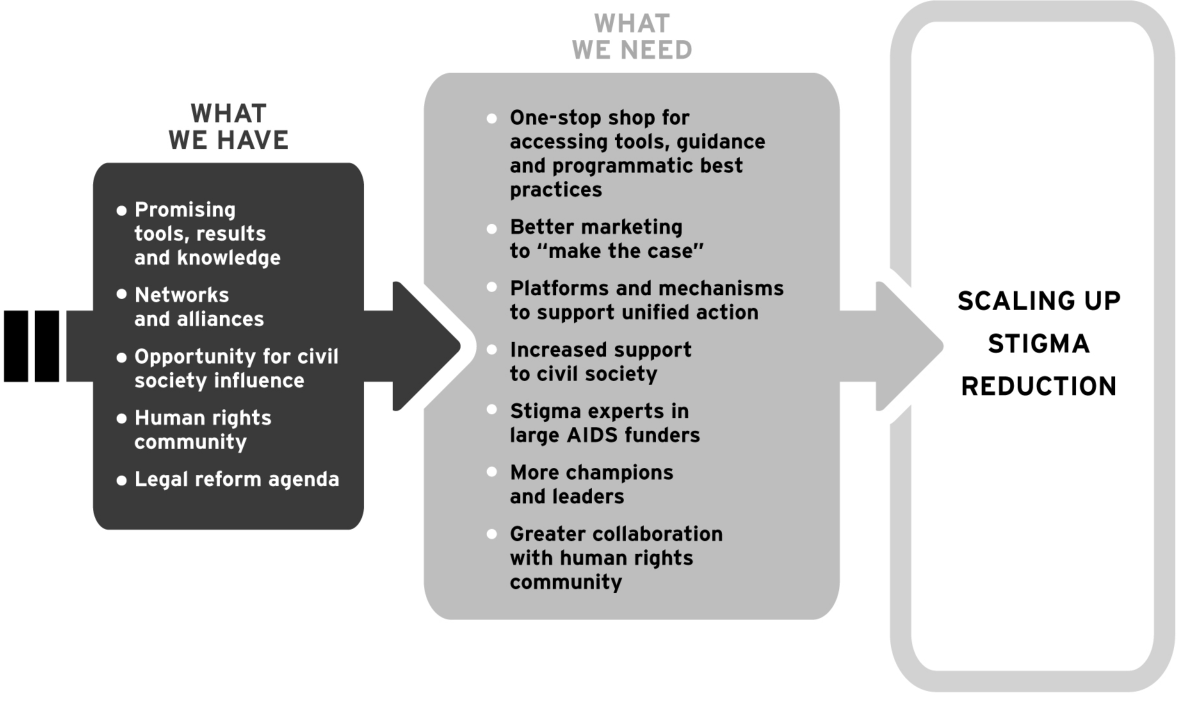
A number of respondents also pointed to the need for concrete models to spur diffusion of new ideas and practices. Demonstration facilities or centers of excellence could showcase nondiscriminatory procedures and practices. Facility-to-facility technical assistance could transfer knowledge and experience to foster scale-up and sustained effort. The need to engage WHO as a standard-setting institution to promote and institutionalize these efforts, taking project work to a global level, was also highlighted by some respondents.

Communications and Advocacy

As noted previously, there is a strong foundation of programming, measurement and guidance tools on or related to HIV stigma to facilitate an expanded response. Yet a commonly expressed concern among scan respondents is that stakeholders may be unaware of existing work, leading to potential duplication of effort and a waste of scarce resources. In addition to doing a better job of communicating and marketing existing work, an expanded response to HIV stigma requires a stronger advocacy effort (see Figure 3 for communications and advocacy facilitators and gaps).

Facilitators include effective models for advocacy and legal reform. For example, advocacy organizations in Nepal convinced the country's Supreme Court to direct the government to end discrimination against lesbian, bisexual and transgender people and ensure rights equal to those enjoyed by heterosexual men and women.[63] Advocacy in China has led to important shifts in policy, including the Ministry of Public Security taking action to promote needle exchange and methadone replacement therapy. The knowledge base in this area is reasonably solid; more than 80 percent of survey respondents agree that "we know what policies could reduce stigma and discrimination for people living with HIV."

FIGURE 3: Communications and Advocacy: Facilitators and Gaps for Stigma Reduction Scale-Up



Another facilitator is that civil society representatives often have opportunities to contribute to country AIDS strategies and plans. Governments are increasingly involving people living with HIV and other vulnerable groups in strategy and programming. Human rights instruments such as Article II of the Universal Declaration of Human Rights offer a framework for action. Programmers and others may access a comprehensive online advocacy toolkit and reference library, focused on eastern and southern Africa, to promote and implement a rights-based approach to HIV and AIDS.[§] Some mechanisms exist, in terms of networks and alliances, to define, champion and execute an advocacy agenda. Resources to capitalize upon include existing human rights instruments and human rights groups, which could be much more strongly involved in efforts to reduce HIV stigma and discrimination.

However, there are barriers to galvanizing political will and reforming laws and policies. A lack of leadership emerged as a major issue; one respondent, referring to government, pointed out, "Stigmatizing statements help people stay in power." Some see the recent growth in discriminatory laws as a major failure in collective effort. Another challenge is a tendency to work in silos, not fully capitalizing on synergies with the human rights community. Among major AIDS bureaucracies, respondents note that, in practice, frameworks still tend to favor quantifiable outcomes over human rights rationales for action. Organizations may silo prevention, care and treatment, which can hinder progress for crosscutting issues such as stigma and discrimination. Decision makers may be under the impression that treatment will "take care of" stigma and discrimination. In light of the economic downturn and the major push for treatment rollout, some see stigma and discrimination programs struggling within the hierarchy of priorities. Key recommendations are described in more detail in the following paragraphs.

- ***Promote the availability of tested tools and approaches***

To capitalize on a growing base of resources and field experiences, there is a great need to more effectively communicate and market existing tools, as well as emerging findings from HIV stigma research. Meeting participants and respondents cited the need for a central repository of knowledge resources that would act as a "one-stop shop" for stigma tools, resources and information and as a place to foster collaboration and information exchange.[64]

[§] www.chr.up.ac.za/undp/index.html

- ***Strengthen advocacy to expand efforts against stigma and discrimination***

Advocacy plays a key role in expansion at various levels. In terms of large-scale expansion, champions are needed to mobilize and articulate a demand for increased attention to and resources for stigma reduction. A unified effort will need to promote concrete efforts in national strategies, plans and proposals to combat stigma and discrimination. It will also require supporters in large funding agencies. Some respondents noted the importance of large funders adding experts in stigma and discrimination within their structures, including technical review panels that vet country proposals. Some respondents called for stigma reduction to be part of all prevention, care and treatment proposals.

Advocacy is also important in strengthening accountability. Strategies and plans need to be translated into concrete action. Although governments may have strong policies on paper, action on the ground may be weak. Some respondents mentioned that a number of countries claim to be doing activities to reduce stigma and discrimination, but what is actually happening in the field remains unclear.

Increasingly, opportunities exist for civil society input and influence. The Global Fund provides avenues for engagement through country-coordinating mechanisms — country-level partnerships that develop and submit grant proposals. Civil society representatives may provide input in areas ranging from proposal development to implementation. Nearly one-third of Global Fund resources go to programs implemented by civil society organizations.[65]

Networks and alliances exist that are taking advocacy efforts forward. But according to a number of respondents, such groups could do much more with increased support, both in terms of funds and capacity strengthening. A number of respondents indicated that some of these groups have difficulty securing the type of funding that would support training and other capacity-strengthening activities and enable a longer-term sustained advocacy effort.

- ***Increase collaboration with human rights groups to assert and protect rights***

Despite the synergies between the human rights and the stigma and discrimination communities, a number of respondents mentioned that the groups often work separately. This concern is echoed more broadly in the recent publication *Verdict on a Virus: Public Health, Human Rights, and Criminal Law:* "There is a need for better coordination between organizations working on human rights and those working on HIV."[66] One scan respondent emphasized the necessity of drawing in other communities: "Structural barriers — specific laws, regulations, policies — make stigma and discrimination valid in the eyes of legal authorities. Public health can not take this on with all of the health care services they are trying to provide."

An important agenda item is legal reform. One respondent noted that barriers such as travel and entry restrictions, HIV criminalization laws, and criminalization of sexual behavior are "at the heart of HIV stigma." Criminalization is on the rise in some settings, which have passed or are considering laws to prosecute HIV transmission or exposure. In West and Central Africa, countries including Benin, Guinea, Guinea-Bissau, Mali, Niger, Togo and Sierra Leone have all passed these types of laws since 2005. A recent estimate counts 31 countries with specific laws that criminalize HIV transmission or exposure, another 27 that have applied nonspecific HIV laws to HIV transmission or exposure, and 35 others that are considering such legislation.[66]

Some laws allow prosecution for having the virus; others prohibit mother-to-child transmission even while many women living with HIV have limited access to adequate health care and infant formula. The intent may be to prevent transmission and exposure and, in some countries, prevent the epidemic from becoming "generalized" in the population. But many experts contend that such laws discourage testing and disclosure, delay treatment, and foster fear and denial. As one respondent noted, "If you have a law that homosexuality is illegal then how do you engage this community?" Women may be disproportionately affected by these laws because they are often more likely to get tested for HIV than men due to greater use of health services, especially antenatal care.[66] In one study in Tanzania, for example, researchers found HIV testing to be four times more common among females as males.[23]

Criminalization of HIV may be particularly damaging for already stigmatized groups, further jeopardizing the health of people most affected by HIV. Many of these groups, such as men who have sex with men, sex workers and injecting drug users, may already be subject to discriminatory laws. In assessing the landscape for lesbian, gay, bisexual and transgender rights, researchers classified 49 out of 80 low- and middle-income countries as highly repressive, with laws that prohibit sexual intercourse between people of the same sex and impose penalties such as death, heavy labor and imprisonment for at least five years.[67]

Legal protections in this area are rare.[66] In Africa, two countries, Namibia and South Africa, offer legal protections against discrimination for lesbian, gay, bisexual and transgender people. In Lesotho, the National HIV and AIDS Policy recommends that the government ensure that HIV services "can be accessed by all without discrimination, including people engaged in homosexual relationships."

Effective strategies for addressing legal and policy reform will vary by setting. In a review of efforts related to sexual diversity, the researchers recommend strategies such as pursuing judicial action in cases where the legislature is unlikely to recognize and support rights, employing regional and global courts to strengthen internal demands for human rights, and joining with other movements for social change to overcome legal barriers. The authors add that it also may be important to demonstrate how legal systems that protect sexual diversity enhance HIV prevention and the health of people living with HIV and AIDS.[67] At the field level, respondents had various suggestions for advancing rights. One respondent, for instance, suggested a hotline on HIV and human rights, along with other care and treatment services. Another respondent suggested more exchange between policy-makers, researchers and clinicians to discuss counterproductive laws, in addition to lobbying at the field level.

Operationally, groups of people living with HIV that are aligned with lawyers' organizations tend to be more successful at legal and policy reform.[68;69] In South Africa, working within the country's progressive democratic and legal systems, the Treatment Action Campaign partnered with the AIDS Law Project to help obtain lower prices for antiretrovirals and other essential drugs. This collaboration defeated an effort to block generics and compelled the government to provide prevention of mother-to-child transmission programs (in 2001) and ART and other essential medicines (in 2003) through the public health care system. The group's vigorous public campaigns and community education efforts are credited with reducing stigma and discrimination and stimulating public demand for litigation.

An expert group formed as part of the aids2031 consortium identified a set of minimal legal standards to reduce vulnerability and to promote respect, protection and fulfillment of human rights. These could constitute a core reform agenda. Recommendations include the following: 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.[57]

- ***Support platforms for unified action***

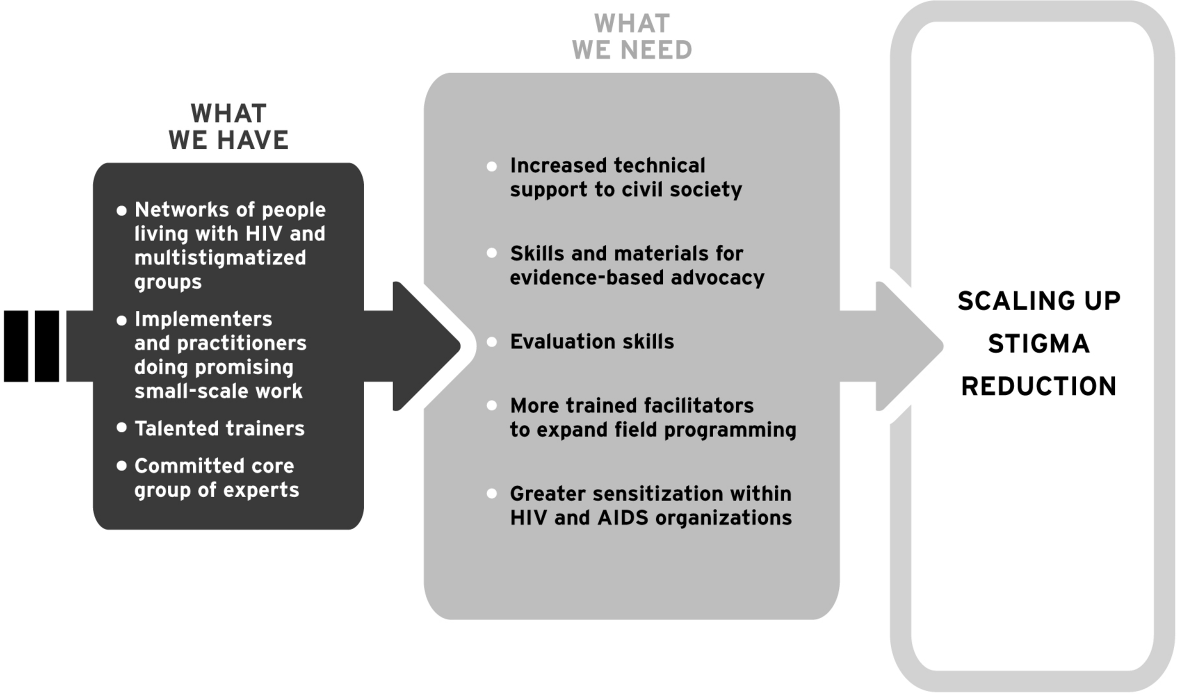
Although major strides have taken place in terms of knowledge and tools, there has been no mechanism to coordinate efforts to promote scale-up of stigma and discrimination reduction. But an expanded response will require stronger collective effort and joint action. This type of action is particularly important in light of a heightened emphasis on institutional and policy change, which tends to require a more systematic, concerted response. Respondents cited the importance of a coordinating body to take these efforts forward. One respondent, for instance, called for an entity to "mobilize the global community around stigma" and coordinate a movement around stigma at the global and country level. Another respondent highlighted as a major barrier to progress "the lack of a unified entity to draft a comprehensive proposal to address stigma and discrimination to submit to high-level policy-makers, and to develop strong training materials and tools to be made available to advocacy or community-based entities to utilize and circulate to their networks."

The nascent Global Network on HIV Stigma Reduction has begun to bring together stakeholders to discuss moving forward with joint action.[64] Key areas of emphasis initially discussed include global knowledge sharing, consolidating measures and measurement tools, developing a global communications strategy, and producing a "what works" compendium. The network has received seed support from the MAC AIDS Fund.

Strengthen Capacity to Drive Expansion

An expanded response to stigma and discrimination, according to most rapid scan respondents, will require capacity strengthening in different areas and among different groups experiencing stigma (see Figure 4 for capacity-strengthening facilitators and gaps). Among survey respondents, the top recommendation for donors was to "support capacity building of organizations to take stigma reduction forward." Specific recommendations are outlined in the

FIGURE 4: Capacity Strengthening: Facilitators and Gaps for Stigma Reduction Scale-Up



following paragraphs.

- ***Increase support for networks of people living with HIV and other vulnerable groups***

Many respondents indicated that involvement of people living with HIV and other stigmatized groups in addressing HIV stigma remains inadequate. This may reflect a broader issue in HIV and AIDS efforts overall. As a recent report, issued from an aids2031 working group on sex, rights and the law, notes, "Despite repeated demands by activist groups and verbal and written commitments by policymakers, meaningful involvement of affected communities in decision-making on the nature of programming and the use of AIDS resources is still not the norm. An investment is required in building the capacity of affected communities and networks to provide leadership and participate fully in developing the AIDS response."[57]

The infrastructure is in place for expanded support and involvement. Networks of people living with HIV span the globe, covering Africa, Asia, the Caribbean, Europe, Latin America and North America. The International Community of Women Living with HIV, an international network run by women living with HIV, has more than 6,000 members from more than 100 countries. Such networks are already actively responding to stigma and discrimination in various ways.

- ***Strengthen skills in evidence-based advocacy***

Overall, respondents pointed to a need for advocacy that includes strategic engagement of policy-makers and influential individuals, effective participation in meetings and consultations, widespread dissemination of key research findings, provision of rigorous inputs into plans and proposals, and activation of networks and coalitions for policy and social change. This implies a number of potential areas for skills building. Some respondents highlighted a specific need to better equip civil society representatives to "make the case" for expanded stigma and discrimination efforts and to influence national strategies, plans and proposals. Other capacity-strengthening areas include strategic planning, convening meetings and negotiating positions, mobilizing different constituencies for joint action, media relations, and effectively communicating different types of evidence to varied audiences.

- ***Enhance capabilities in evaluation***

Few stigma and discrimination interventions have been evaluated, which hampers further expansion of work in these areas. A number of respondents pointed to the need to build field capacity in measurement and evaluation. Some noted that their own organizations could not undertake a rigorous evaluation without technical assistance. Survey respondents were evenly split on whether "we know how to measure stigma and evaluate programs," with 41 percent expressing agreement and the same proportion disagreeing. Needs in this area will vary by organization, but may include training and skill building in evaluation design, implementation and analysis.

- ***Increase the number of trained facilitators to support program rollout***

Effective programming requires talented and insightful facilitators. As is the case in many areas of social change, altering attitudes and behaviors related to stigma is not just a matter of conveying information and facts. Field studies from various countries suggest effective programming inspires people to critically reconsider deeply held beliefs. The best facilitators have likely undergone this reflective process themselves, examining and unpacking their own prejudices. Respondents involved in field programming mentioned the need for more resources directed toward identifying and training facilitators. This would provide the human capital for expanding stigma reduction programming and conducting ongoing training to integrate stigma reduction more broadly into HIV and AIDS programming, including treatment services.

Another important barrier mentioned by respondents is the need for capacity strengthening in HIV stigma and discrimination within organizations involved in prevention, care and treatment. Some mentioned that some such organizations are not as sensitive as they might be to stigma and discrimination issues. One respondent, for instance, noted, "We are not progressing on the ground because the leadership within the implementing bodies does not understand stigma. . . . In order to work on stigma we need to work on underlying issues of homophobia. . . . If people within organizations of human rights and HIV can not talk about these issues then how can we make a change in the communities?"

Conclusion

> 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[70]

The challenges posed by stigma and discrimination remain serious and pressing, not only in terms of achieving the global goals related to the pandemic but in advancing the health and rights of all those affected by HIV. Despite the best efforts of champions such as DFID and UNAIDS and alarms raised by front-line HIV workers, the response to stigma and discrimination remains relatively small-scale. The experiences of far too many people living with HIV are reflected in the concerns expressed by this woman from Vietnam: "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."[17]

At the same time, an increasing number of facilitators exist to support an expanded effort. The field has actionable knowledge and effective tools as well as champions and networks to take this work forward. There is increasing clarity about priorities and next steps for achieving scale — a blueprint for action in areas ranging from the evidence base to advocacy and communications. In addition, the store of research results on effective approaches to stigma reduction is growing.

The findings from this analysis provide strategic direction for expanding the response to HIV stigma and discrimination. To move the field forward, donors, researchers, programmers and advocates now need to work together to build the evidence base, promote tools and approaches and develop new ones as needed, mobilize actors to counter discriminatory laws and policies, and build capacity among key groups.

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