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SCALING UP POLICIES, INTERVENTIONS, AND MEASUREMENT FOR STIGMA-FREE HIV PREVENTION, CARE, AND TREATMENT SERVICES

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Scaling Up Policies, Interventions, and Measurement for Stigma-Free HIV Prevention, Care, and Treatment Services

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Acknowledgments

In September 2011, the Health Policy Project convened representatives from 14 international organizations to discuss and build consensus on “Measuring HIV-related Stigma and Discrimination in Healthcare Settings.” This paper builds on the thoughtful deliberations and insights of the 22 participants, who included experts in public health, HIV, stigma and discrimination, measurement, monitoring and evaluation, and programming. The authors thank all the participants for their time and valuable contributions. The authors also thank Anita Bhuyan, Ron MacInnis, and Beth Robinson of Futures Group and colleagues from the United States Agency for International Development (USAID) for their comprehensive comments and revisions, which significantly strengthened the paper. The authors also gratefully acknowledge USAID and the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) for their leadership, contributions, and support to stigma and discrimination work globally over the past decade. The progress made in programmatic tools, intervention models, and measurement for stigma reduction would not have been possible without the leadership and support of USAID.

Executive Summary

HIV-related stigma and discrimination (S&D) are widely recognized as key barriers to the use of HIV care, support, and treatment programs, thereby fueling the spread of HIV. The experience and fear of S&D can deter people, particularly populations most at risk for HIV, from (1) seeking and accessing HIV testing; (2) disclosing their HIV status; (3) accessing and practicing prevention; (4) accessing care; and (5) adhering to treatment. Stigma and discrimination exist across many social settings, including the household, workplace, community, places of worship, and healthcare facilities and are often experienced as layered or intersecting when an individual or group is identified as belonging to more than one stigmatized group (e.g., living with HIV and being a pregnant woman, a drug user, or a male who has sex with males). Stigma and discrimination in healthcare facilities is particularly damaging because it is in health facilities that people living with HIV seek care and treatment to remain healthy and others seek information, counseling, testing, and other prevention services.

The scale-up of programs to reduce S&D in health facilities is urgently needed to (1) improve the quality of care delivered; (2) improve the lives of clients; (3) uphold the human right to healthcare; and (4) maximize investments in prevention, care, and treatment programs. While much progress has been made in developing programmatic training tools and models for reducing S&D in healthcare facilities, such programs have not yet been routinely institutionalized and scaled up. A key factor contributing to this gap between recognized need and scaled-up action is the lack of a brief, globally standardized set of measures for HIV-related stigma and discrimination in healthcare facilities and among healthcare workers.

In response to this need, the Health Policy Project (HPP) is leading an ongoing collaborative global effort to develop a brief, standardized set of HIV-related S&D measures for use in healthcare facilities. As part of this effort, this paper presents a review of the literature on measuring HIV-related S&D in health facilities and presents a framework for HIV-related S&D reduction programmatic intervention and measurement. The framework delineates key programmatic areas (drivers) for intervention and identifies the key points within the framework where measurement should occur.

To achieve healthcare facilities free of HIV-related stigma and discrimination, individuals and institutions need to bring together current learning on how to programmatically reduce HIV-related S&D in facilities, while undertaking systematic measurement to provide the necessary evidence for strategic and effective action. An important element in this effort will be to generate data to monitor and evaluate progress and thereby hold governments, health facilities, and their staff accountable for providing non-stigmatizing and non-discriminatory care for all clients, particularly people living with or most at risk for HIV.

The scale-up of programs to reduce HIV-related stigma and discrimination in healthcare facilities is essential to maximize investments in prevention, care, and treatment programs. To achieve this, the following steps are recommended:

1. Develop standardized measures for HIV-related stigma and discrimination in healthcare facilities.
2. Develop and implement national- and facility-level policies to support the provision of healthcare free of HIV-related stigma and discrimination.
3. Develop and implement operational policies and practices at the healthcare facility level to ensure that the environment supports staff to provide non-stigmatizing and non-discriminatory care.
4. Set specific targets, allocate funding, and measure successes and challenges toward reducing HIV-related stigma and discrimination.

Introduction

HIV-related stigma and discrimination (S&D)¹ are widely recognized as key barriers to the use of HIV care, support, and treatment programs, thereby fueling the spread of HIV. The experience and fear of S&D can **deter people from** (1) **accessing HIV testing** (Wolfe et al., 2006; Kalichman and Simbayi, 2003; Liu et al., 2005; Pulerwitz et al., 2008); (2) **disclosing their HIV status** (Nyblade et al., 2005; Medley et al., 2004; Andrewin and Chien., 2008); (3) **accessing and practicing prevention** (Campbell et al., 2005; Kalichman and Simbayi, 2003; Smith and Morrison, 2006); (4) **accessing care** (Kinsler et al., 2007); and (5) **adhering to treatment** (Mills, 2006; Horberg et al., 2008). Stigma and discrimination exist across many social settings, including the household (Jain et al., forthcoming), workplace (Rao et al., 2009), community (Nyblade et al., 2008), and places of worship (UNAIDS et al., 2011).

The prevalence of HIV-related S&D in healthcare facilities is also well-documented across a wide range of country and epidemic settings (Oanh et al., 2008; Nyblade et al., 2005; Mahendra et al., 2007; Nguyen et al., 2008; Turan et al., 2008; Letamo, 2005; Reis et al., 2005). Stigma and discrimination in healthcare facilities is particularly damaging because it is in health facilities that people living with HIV seek care and treatment to remain healthy and others seek information, counseling, testing, and other prevention services.

The scale-up of programs to reduce S&D in health facilities is urgently needed to (1) improve the quality of care delivered; (2) improve the lives of clients; (3) uphold the human right to healthcare; and (4) maximize investments in prevention, care, and treatment programs. While much progress has been made in developing programmatic training tools and models for reducing S&D in healthcare facilities, such programs have not yet been routinely institutionalized and scaled up. A key factor contributing to this gap between recognized need and scaled-up action is the lack of a brief, globally standardized set of measures for HIV-related stigma and discrimination in healthcare facilities and among healthcare workers (Carr et al., 2010; MAC AIDS Fund and ICRW, 2008; ICRW and London School of Hygiene & Tropical Medicine, 2010). Measurement of stigma and discrimination in healthcare facilities is crucial to catalyzing the scale-up of programmatic action. It provides policymakers, governments, donors, and civil society advocates with the necessary data to document need, drive evidence-based advocacy, develop strategic policies, monitor and evaluate progress, and implement effective programs that uphold the rights of people living with HIV and other key populations affected by HIV.

In response to this need, the Health Policy Project (HPP) is leading an ongoing collaborative global effort to develop a brief, standardized set of HIV-related S&D measures for use in healthcare facilities. In September 2011, HPP convened 22 experts from 14 international organizations² to review existing measures and build consensus toward a recommended and consolidated set of measures. The outcome of the meeting was a brief survey tool, which is currently being tested and validated in multiple country settings and will be finalized based on the results (Nyblade and Hunger, 2012).

¹ We define HIV-related stigma and discrimination (S&D) to include S&D toward people living with HIV, as well as S&D toward people or groups often associated with HIV, particularly males who have sex with males, transgender persons, sex workers, and people who inject drugs.

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Scaling Up Policies, Interventions, and Measurement
for Stigma-Free HIV Prevention, Care, and Treatment Services

To catalyze discussion and movement, we conducted a literature review and synthesis of current available knowledge on the measurement of HIV stigma and discrimination in healthcare facilities. Based on this review, we prepared a programmatic and measurement framework for action. Recommendations and crucial next steps based on the review and framework are presented in this paper to facilitate progress toward achieving healthcare services free of stigma and discrimination.

Background

Stigmatizing and discriminatory behaviors occur among all levels of staff at a healthcare facility (Li et al., 2007; Oahn et al., 2008)—from doctors and nurses to registration clerks, lab technicians, pharmacists, and security guards—and may convey an unwelcoming and potentially unsafe and uncaring atmosphere, particularly for HIV-positive clients and clients from key populations. This can influence whether HIV-positive and other clients seek the prevention, care, treatment, and support they need.

Stigma and discrimination experienced by people living with HIV in healthcare settings take on many forms. Research has shown that people living with HIV have been refused services, denied medicine, and passed from provider to provider (Brickley et al., 2008; Thi et al., 2008; Varga and Brooks, 2008). In addition, healthcare providers have isolated HIV-positive clients from HIV-negative clients and disclosed sero-positive status to family members without their clients' consent (Mahendra et al., 2007; Kamau et al., 2007; USAID | Health Policy Initiative, Task Order 1, 2007). Moreover, healthcare workers have been reported to use double gloves during non-invasive tasks like changing bed sheets or taking the blood pressure of an HIV-positive client (Oahn et al., 2008), an unnecessary precaution that can visibly mark a client as HIV positive.

While the negative effects of HIV-related stigma and discrimination for clients in healthcare facilities are widely recognized, the impact on healthcare providers is also important to recognize, as this too affects the care and treatment provided and the well-being of providers.

Research has shown that healthcare providers and staff also experience stigma—including from colleagues, the community, and family members—due to their association and support of people living with HIV (UNAIDS et al., 2009; USAID | Health Policy Initiative, Task Order 1, 2010; Holzemer et al., 2007). Referred to as “secondary” or “courtesy” stigma, providers have reported perceived and experienced secondary HIV stigma (Delobelle et al., 2009; Holzemer and Uys, 2004; Sofolahan et al., 2011), which decreases their job satisfaction (Chirwa et al., 2009) and increases job stress (Pleck et al., 1988; Dieleman et al., 2007). In countries where the HIV epidemic is large and the caseload is overwhelming, provider “burnout” and emotional stress have been documented (UNAIDS, 2000; Kruse et al., 2009; Hayter, 1998). Perceived and experienced stigma may lead healthcare staff to quit their jobs or

Definitions

Stigma: Is a social process of devaluing persons, beginning with marking or labeling of differences, attributing negative connotations or values to those differences, leading to distancing and separation of the person and culminating in discrimination.

Anticipated stigma: Real or imagined fears of societal (e.g., family, community, healthcare professionals) attitudes and behaviors if HIV or other stigmatized behavior (e.g., drug use) is disclosed.

Experienced stigma: Forms of stigmatizing behaviors or discrimination that are not typically actionable under law and experienced by people living with HIV or individuals associated with HIV, such as family members or healthcare providers.

Secondary stigma: Stigma experienced by individuals who are associated with people living with HIV (e.g., family, partners, friends, healthcare professionals).

Internalized stigma: Acceptance by the self that the external stigma is true and justified—of society's judgment of oneself as being of a “lesser status.” Can manifest in low self-esteem and sense of worth, self-blame, and self-isolation/withdrawal.

Compound/Layered stigma: Experience of multiple stigmas (e.g., stigma toward men who have sex with men, transgenders, migrants, poor women, people who inject drugs plus HIV stigma).

Observed stigma: Forms of stigma witnessed by an individual (e.g., nurse gossiping about a client's HIV status as seen by a lab technician).

Discrimination: Unfair and unjust treatment of an individual on the basis of a real or perceived status or attribute (e.g., HIV status or association with HIV-positive individuals). Discrimination is typically actionable under law.

transfer out of departments that provide care to HIV-positive clients. They may also be reluctant to have an HIV test or, if positive, to seek care and treatment.

The increase in data on the presence and consequences of stigma and discrimination in healthcare facilities has resulted in a growing evidence base on the effectiveness of interventions to reduce S&D toward clients in these settings (Uys et al., 2009; Oanh et al., 2008; Mahendra et al., 2007; Murphy et al., 2000, Pisal et al., 2007). Research suggests that stigma and discrimination needs to be addressed at the individual, environmental, and policy levels (Nyblade et al., 2009; Holzemer, et al., 2007).

Three immediate actionable drivers or causes of HIV stigma and discrimination in healthcare facilities have been identified: (1) **lack of awareness** of stigma and discrimination and its damaging affects; (2) **fear of contact** with HIV-positive individuals due to a lack of HIV transmission knowledge; and (3) values linking **assumed improper or immoral behaviors** to people living with HIV (Nyblade et al., 2009). Researchers have shown that interventions can increase healthcare providers' awareness of the forms of stigma and discrimination (Oahn, 2008), reduce their fears related to HIV transmission (Ezedinachi et al., 2002), and address attitudes and assumptions about the behavior and moral character of people living with HIV (Adebajo et al., 2003). Researchers have also observed providers' need for information and training, supplies, and supervision and support to enable them to perform their duties aptly while practicing universal precautions and prevention of HIV transmission (Oahn et al., 2008). Lastly, studies have shown the need for non-discriminatory policies coupled with standard procedures and universal precautions in order to offer high-quality services to HIV-positive clients (Wu et al., 2008).

Methods

A literature review was conducted in PubMed, Scopus, PsychINFO, and Google Scholar using the following key terms: HIV stigma, AIDS stigma, discrimination, measurement, scale, index, healthcare facility, nurse, provider, and provider attitude. Articles were included in this analysis if they met the following criteria: (1) measured HIV stigma and discrimination in healthcare settings from the perspective of any healthcare facility personnel who offers care to people living with HIV, including providers, nurses, and lab technicians, and (2) developed a scale or index to measure any aspect or domain of HIV stigma and discrimination among workers in healthcare facilities. We were interested in all articles published in this area to date and therefore did not include any limits on year of publication or country where research was implemented. Additional articles were added to the analysis based on a scan of selected articles' reference lists. Further papers were obtained from a grey publication search that included evaluation reports, white papers, presentations, and poster presentations. These articles were acquired from an existing database at the Health Policy Project, the Stigma Action Network website,³ and through the research community represented at the September 2011 meeting organized by HPP. A total of 18 articles were included in this analysis.

³ <http://www.stigmaactionnetwork.org/web/guest/home;jsessionid=5C833F89D315DB1421ECB951A86F634C.node1>.

Results

Measuring HIV Stigma and Discrimination in Health Settings: State of the Field

Over the past several decades, various stakeholders have developed and tested scales to assess HIV-related stigma and discrimination in healthcare facilities. The majority of scales focus on assessing stigmatizing attitudes and behaviors of healthcare providers toward HIV-positive clients. A few scales also assess providers' experiences of secondary stigma.

The first measurement of healthcare provider attitudes toward HIV-positive clients was conducted in the United States in the early 1990s. The AIDS Attitude Scale (AAS) was originally implemented among nurses and included 21 attitudinal items on a six-point Likert scale (Froman et al., 1992; Froman and Owen, 1997). The subsequent AIDS Attitude and Conservative Views Scale (Harrison et al., 1994) included 11 items on a five-point Likert scale. Both scales captured providers' willingness to give care to and empathize with people living with HIV. The AIDS Attitude and Conservative Views Scale included items of sympathy toward males who have sex with males and people who inject drugs, while the AAS measured negative attitudes like blame and HIV as a deserving consequence for immoral behaviors among these population groups. The AAS also includes a question related to the criminal prosecution of HIV-positive women who choose to have children. Unlike the AAS, the AIDS Attitude and Conservative Views Scale separates behavioral intentions from attitudes. Since these initial scales, considerable work has been done to advance the measurement of HIV-related stigma and discrimination among healthcare providers.

The more recent measurements capture broader domains of HIV stigma. For example, scales now include aspects of HIV transmission knowledge, fear of HIV transmission while caring for HIV-positive clients, and institutional responsibility to develop and implement policies to protect HIV-positive clients from discrimination. Results from our review are organized by the **four key areas most studies measured**. These areas include both drivers and manifestations of HIV-related stigma and discrimination. The first three correspond to the actionable S&D drivers, where most programmatic action to reduce stigma and discrimination in health facilities focuses, while the last measures manifestations:

1. Fear of HIV infection (includes knowledge of HIV transmission)
2. Attitudes/value-driven stigma (e.g., stereotypes and prejudices)
3. Institutional-level facilitators and barriers (e.g., policies to protect people living with HIV and to create a safe work environment)
4. Observed and anticipated stigma and discrimination, including secondary stigma

Individual-level driver: Fear of HIV infection

The studies reviewed captured three general domains of fear of HIV infection among healthcare providers:

1. Fear of HIV transmission through casual contact with an HIV-positive individual (Varas-Diaz and Neilands, 2009; Stein and Li, 2008; Oanh et al., 2008)
2. Fear of HIV transmission in work-related situations (USAID | Health Policy Initiative, Task Order 1, 2010; Nyblade et al., 2005; Oanh et al., 2008)

3. Fear of HIV transmission while using healthcare facilities where people living with HIV are also clients or providers are HIV positive, as assessed among healthcare providers (Varas-Diaz and Neilands, 2009)

Casual contact. The studies measuring the irrational fears of HIV transmission through contact with HIV-positive individuals in everyday situations sought to measure healthcare providers' perspectives and fears beyond the healthcare setting. These items tended to capture the myths and misconceptions about HIV transmission that exist more broadly in society. This was done by asking respondents about hypothetical situations in which they would interact with people living with HIV, such as *sharing meals or utensils/glassware, buying food from a vendor who is HIV positive, or touching the sweat or saliva of someone living with HIV* (Nyblade et al., 2005; Stein and Li, 2008; Mahendra et al., 2007; Abell et al., 2007).

Work-related situations. Several reviewed studies developed items and scales that assessed feelings of fear when performing certain work-related activities—both non-invasive (so no risk of infection) and invasive procedures. Examples of items that capture non-invasive tasks are fear of HIV transmission when *taking the blood pressure of a person with HIV or AIDS* or *changing the clothes of a person with HIV or AIDS* (Oanh et al., 2008). Examples of invasive items include the fear of HIV transmission when *dressing the wound of a person with HIV or AIDS* (Nyblade et al., 2005) or *assisting in the delivery of an HIV-positive woman* (USAID | Health Policy Initiative, Task Order 1, 2010). In an internet-based study (USAID Health Policy Initiative, 2010), researchers framed fear-related questions a bit differently and asked providers if they “felt safe” performing particular functions as opposed to “had fear.” Two studies assessed “perceived risk” of HIV transmission while conducting different work-related tasks (Lohiniva, 2011; Li et al., 2007). Healthcare providers were asked to rate the degree of risk they believed was associated with a range of statements including *accidentally pricking yourself with a needle used on a patient with AIDS* and *cleaning and dressing a wound for an HIV-positive patient*.

Use of healthcare services. Only one reviewed study asked healthcare providers about their comfort in (1) using healthcare services where HIV-positive people receive care or (2) obtaining services from HIV-positive providers (Varas-Diaz and Neilands, 2009). These items placed the healthcare provider in the position of a healthcare seeker and therefore uncovered feelings and notions of risk and behaviors that lead to HIV stigma. Item examples included “*I would feel comfortable being operated on by a surgeon with HIV/AIDS*” and “*I would use the services of a dentist that sees many people with HIV/AIDS.*”

Individual-level driver: Attitudes and value-driven stigma

The majority of the reviewed studies included measurements that assessed value-driven stigma among healthcare providers. The measurements capturing this construct included aspects of the following (Varas-Diaz and Neilands, 2009; Rutledge et al., 2011; USAID | Health Policy Initiative, Task Order 1, 2010; Stein and Li, 2008; Varga and Brooks, 2008; Ekstrand et al., 2011; Oanh et al., 2008; Nyblade et al., 2005):

- Blame and responsibility
- Shame
- Empathy

While some studies measured blame and shame as separate constructs, others combined these two aspects for a higher-level construct such as general prejudicial attitude (Li et al., 2009).

Blame and responsibility. As with the initial scales developed by Froman and colleagues (1992) and Harrison and colleagues (1994), blame was captured through providers' opinions and stereotypes regarding perceived immoral or deviant behaviors that can lead to HIV acquisition, such as promiscuity, sex work, injecting drug use, and same sex relationships. Measures of blame also include judgments about the personal responsibility for acquiring HIV as a consequence of these behaviors. Item examples ranged from "*PLHA are responsible for having their illness*" (Abell et al., 2007) to "*infection with HIV is a direct result of people's promiscuity*" (Varas-Diaz and Neilands, 2009) to "*people who got HIV/AIDS through sex and drug use, got what they deserved*" (Stein and Li, 2008) to "*homosexuals are predominantly responsible for the HIV/AIDS epidemic*" (Varga and Brooks, 2008). In several of the reviewed studies, blame and responsibility were also directed at HIV-positive women or parents who choose to have children (Lohiniva, 2011; O'Hea et al., 2001).

Shame. Studies that included aspects of shame in their measurements assessed healthcare provider attitudes of how people living with HIV should feel, specifically feelings of shame if tested positive for HIV. These items are asked from both a general and personal viewpoint. An example of a general perspective item is "*People living with HIV should feel ashamed of themselves,*" while two examples of personal perspective items are "*I would feel ashamed if I was infected with HIV*" and "*I would feel ashamed if someone in my family was infected with HIV*" (USAID Health Policy Project, 2010; Nyblade et al., 2005; Li et al., 2009; Stein and Li, 2008).

Empathy. While empathy toward people living with HIV was not found to be measured widely in the reviewed studies, several studies developed measurement constructs for emotions associated with people living with HIV (Varas-Diaz and Neilands, 2009; O'Hea et al., 2001). Researchers attempted to capture the empathy construct of sympathy or compassion toward HIV-positive people. Examples of these types of statements are people "*infected through drug use deserve sympathy*" (Stein and Li, 2008) and "*I feel sorry for people who have HIV/AIDS*" (Varga and Brooks, 2008).

Institutional-level drivers

Few items are currently available to adequately examine institutional-level drivers of HIV stigma and discrimination in healthcare facilities. The few studies that captured this domain generally asked providers whether policies to protect HIV-positive clients from discrimination existed at their healthcare facility and the extent to which these policies were enforced (Nyblade et al., 2005; Oahn et al., 2008; Lohiniva, 2011). One study inquired about 12 specific policies, guidelines, or protocols (USAID | Health Policy Initiative, Task Order 1, 2010).⁴ Providers in this study were then asked if they had received training on implementing the policies. Another study asked providers about the availability of (1) equipment and supplies like sterile needles, rubber gloves, and disposable containers; (2) HIV testing and treatment to healthcare providers; and (3) health insurance coverage if a provider was infected with HIV on the job (Li et al., 2009). The majority of studies demonstrated a clear lack of institutional support to healthcare facility staff in caring for people living with HIV; this was most evident in the lack of

⁴ Policies included (1) national HIV policy, (2) HIV counseling and testing, (3) HIV testing procedure, (4) confidentiality, (5) informed consent, (6) post-exposure prophylaxis, (7) national clinical HIV guidelines, (8) treatment of opportunistic infections, (9) national clinical TB guidelines, (10) blood safety, (11) universal precautions, and (12) non-discrimination against people living with HIV.

institutional-level policies on universal precautions, informed consent, and clients' rights to care and the lack of supplies and materials.

Stigma manifestations: Observed stigma and discrimination and anticipated and experienced secondary stigma

Several studies used quantitative measures to assess observed stigma and discrimination in healthcare facilities and willingness to treat among healthcare providers. Items measuring observed discrimination asked providers if they had seen other nurses or staff behave in certain ways, such as making HIV-positive clients wait to receive care (Uys et al., 2009), testing a client for HIV without his/her consent (Nyblade et al., 2005), and referring an HIV-positive client to another facility or provider to avoid providing them with care (Oanh et al., 2008). These studies asked respondents what they had observed happening, as opposed to whether they themselves had carried out stigmatizing or discriminatory acts, because of expected social desirability bias—that healthcare providers would not answer truthfully about their own behavior. Studies that assessed providers' willingness to treat or provide care to HIV-positive clients asked a set of hypothetical statements. These measures included *working with HIV-positive clients in the same way as other clients* (Li et al., 2009), *conducting a physical exam on an HIV-positive client* (Stein and Li, 2008), and *keeping HIV-positive clients waiting for care in the lobby* (Rutledge et al., 2011).

A limited number of the reviewed studies measured healthcare providers' anticipated (felt) secondary stigma, as well as experienced secondary stigma. Items that have been developed to explore anticipated secondary or courtesy stigma have gauged providers' perspectives of how their sexual partners, family members, and society view their work with HIV-positive clients: *"I have felt that people are afraid of me because they think they can get HIV from me because I care for people living with HIV"* (USAID | Health Policy Initiative, Task Order 1, 2010). Providers have also been asked about their personal experiences with stigma and discrimination as a result of their work with people living with HIV: *"I have lost friends because I told them that I provide care to people living with HIV"* (USAID | Health Policy Initiative, Task Order 1, 2010). Measurement of the potential effects of anticipated secondary stigma has also been captured: *"If [I] worked with HIV-positive patients, [I would] want to change jobs"* (Stein and Li, 2008). These measures attempted to capture the negative consequences or association providers anticipate and experience for their work with HIV-positive clients.

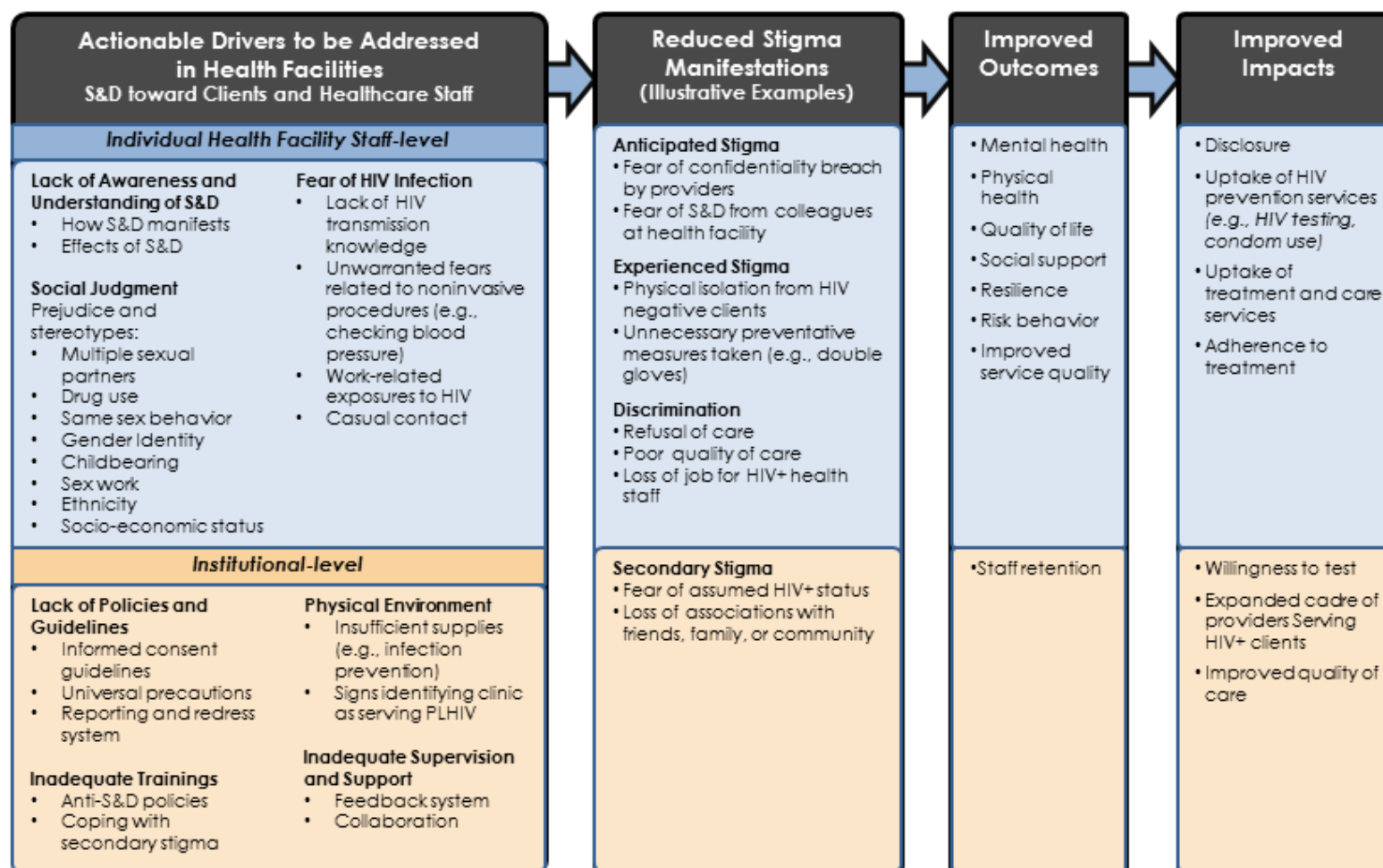
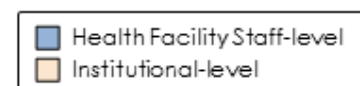
A Framework for Action

The integration of systematic measurement into programs working to reduce HIV stigma and discrimination in healthcare facilities is essential for shaping effective evidence-based programs, measuring progress, and evaluating success. In turn, S&D reduction contributes to the improvement of all HIV-related program outcomes and impacts. To help policymakers and programmers understand both the pathways through which stigma and discrimination contribute to larger outcomes and impacts, as well as the specific entry points for programmatic intervention and measurement, we developed a framework for addressing and measuring stigma and discrimination in healthcare facilities (see Figure 1 on the following page). The framework delineates key programmatic areas (drivers) for intervention and identifies the key points within the framework where measurement should occur.

The framework reflects the collective findings and outcomes of the September 2011 meeting held by HPP (Nyblade and Hunger, 2012), the knowledge gained from the review of existing measurement tools, and the analysis of successful interventions and best practices. It is based on and combines the clients' rights and healthcare staff needs framework (Huezo and Diaz, 1993) and "Reducing HIV Stigma and Discrimination: A Framework for Program Implementation and Measurement" developed by the Global Stigma Indicators Working Group (Stangl et al., 2010). Taking into consideration that staff in healthcare facilities can be both perpetrators and recipients of stigma and discrimination, this framework incorporates a focus on both clients and healthcare staff. It is based on clients' rights to confidentiality and privacy when seeking care and support, as well as the needs of healthcare staff for appropriate training, skills, and tools to provide the services clients have the right to. It also takes into account that staff in health facilities can be subject to stigma and discrimination, as providers of care for people living with HIV, or because they themselves are living with HIV. Lastly, while not depicted in Figure 1, the environment plays an important role in shaping staff behavior. Recognizing that providers are part of and influenced by the environment beyond the healthcare facility, the framework should be placed in the larger social context of changing socio-cultural facilitators. These facilitators include the economic and political environment, gender and sexual cultures prevalent in society, health beliefs, ethics, and religion. Though not represented in the framework, it is important to note that direct engagement between healthcare staff and people living with HIV occurs beyond the healthcare facility and that this engagement can influence providers' attitudes and behaviors toward people living with HIV.

To capture the importance of programmatic interventions at both the individual staff level and institutional or environmental level, the actionable drivers for reducing stigma and discrimination are divided into two sections. Measurement of the key drivers at both these levels is essential to supporting effective programming. The first section (top part of the box) focuses on key drivers to address at the individual level. Example interventions to address these drivers include (1) creating awareness and understanding of how S&D manifest in healthcare facilities and the impact; (2) deepening knowledge of HIV transmission and prevention to address unwarranted fears of transmission; and (3) addressing attitudes and social judgments about clients living with or affected by HIV.

A Framework for Addressing and Measuring Stigma & Discrimination in Healthcare Facilities¹



¹ While not depicted, as the focus of figure 1 is on provision of key entry points for immediate action and measurement on S&D in health facilities, it is important to note that the environment outside the health facility plays an important role in shaping staff behavior and facility environment. Therefore, the framework is embedded in the larger social context of changing socio-cultural barriers and facilitators. These include the economic and political environment, gender and sexual cultures prevalent in society, health beliefs, ethics, and religion.

The second section (bottom part of the box) delineates the key drivers to address at the institutional or environmental level. Addressing these drivers will not only help reduce stigma and discrimination but also provide the support that facility staff need to offer safe and welcoming services to HIV-positive clients. Interventions to address these drivers focus on policies and guidelines, training, supplies, and supervision and support. For example, policies and guidelines related to informed consent procedures and infection prevention not only need to be in place at healthcare facilities, but they also need to be implemented and all staff should be trained in them. Staff training should include standard reporting procedures for violations of policies, clinical guidelines, and coping mechanisms to deal with secondary stigma. Institutional support includes acknowledgment of secondary stigma and the recognition that providers may also need counseling and assistance to manage secondary stigma. To provide non-stigmatizing care and treatment, sufficient supplies (e.g., post-exposure prophylaxis and latex gloves) should be available to providers for correct implementation of universal precaution and the physical environment must be free of visible identification of HIV-positive clients (e.g., visible marking on charts, rooms labeled “HIV Clinic”). Finally, to improve the services they offer, healthcare providers need effective supervision and support to freely air concerns and ask questions about HIV care without judgment or fear of reprisal.

Manifestation of stigma is the second place in this framework where measurement occurs, providing the levels or “prevalence” of the different forms of stigma (including anticipated, experienced, and secondary stigma) and discrimination—whether related to HIV status or to being identified as a member of a key population or other stigmatized groups. When programmatically addressed and measured, the actionable drivers lead to reductions in the marking of individuals as “different,” potentially “dangerous,” and as socially “undesirable” or “deviant” due to assumed behaviors or characteristics associated with being HIV positive. The stigma of being HIV positive often intersects with or overlaps with other stigmas associated with HIV (e.g., being a drug user, migrant, sex worker, transgender, poor woman, male who has sex with men, or sexually active young person). Programs seeking to effectively reduce HIV-related stigma and discrimination will need to address not only HIV stigma but also these associated and intersecting stigmas.

Diminishing individual anticipation of stigma and discrimination can contribute to increases in HIV testing, treatment, and care, especially if individuals are less afraid of others knowing their HIV status. In the healthcare facility setting, this can include clients anticipating stigma and discrimination by staff or HIV-positive staff fearing stigma from their colleagues. Experienced stigma manifests in myriad ways, including gossiping and labeling, physical isolation from HIV-negative clients, sub-standard care, and breaches of confidentiality. Discrimination is separated out from experienced stigma to delineate stigmatizing acts that may be legally actionable in many countries (e.g., refusal of care or loss of employment for being HIV positive) versus other behaviors that are generally not legally actionable (e.g., gossiping or making people living with HIV wait longer for care). Reductions in discrimination and anticipated and enacted stigma can all lead to improved outcomes such as better mental and physical health and improved quality of life. These, in turn, contribute to such behaviors as disclosure and uptake of HIV prevention, care, and treatment services.

While this framework presents the key areas for programmatic intervention and the pathways through which stigma and discrimination influence key health outcomes, it also emphasizes where S&D measurement must occur. The first area is at the level of the actionable drivers and focuses on the

programmatic elements of stigma reduction programming. The second area is at the level of the manifestations of stigma and offers a metric to gauge levels of the different forms of S&D as experienced by those being stigmatized. Taken together, key measures in these two parts are necessary for programs to monitor and evaluate their progress in reducing stigma and discrimination and build the evidence base for action.

Conclusion and Recommendations

Deliberate, measurable strategies for reducing HIV-related stigma and discrimination toward people living with or affected by HIV in healthcare facilities are fundamental to improving access to life-saving and sustaining prevention and treatment services. Progress to date in developing and testing programmatic tools and strategies for the reduction of HIV-related stigma and discrimination, as well as advances in measurement, provide a strong foundation for closing the gap between recognition of the need to address S&D and scaled-up action to do so. While recognizing that the broader social and cultural contexts are critical in shaping health facility staff behaviors, facility policies, and the environment within the facility, our review seeks to prioritize the role of the health sector in operationalizing and measuring HIV-related stigma and discrimination reduction. In light of the evidence, we provide a practical framework for action that healthcare providers and healthcare facilities will see as immediately actionable and concrete.

To achieve healthcare facilities free of HIV-related stigma and discrimination, individuals and institutions need to bring together current learning on how to programmatically reduce S&D in facilities, whether toward people living with HIV or key affected populations, while undertaking systematic measurement to provide the necessary evidence for strategic and effective action. An important element in this effort will be to generate data to monitor and evaluate progress and thereby hold governments, health facilities, and their staff accountable for providing non-stigmatizing and non-discriminatory care.

The scale-up of programs to reduce HIV-related stigma and discrimination in healthcare facilities is essential to maximize investments in prevention, care, and treatment programs and requires the collective effort of multiple groups, including policymakers and national programs, health facilities and facility staff, medical training schools and medical associations, civil society, researchers, and donors. To achieve this, the following steps are recommended for each group:

Policymakers and national programs

- Develop and implement national- and facility-level policies to support the provision of healthcare free of stigma and discrimination in collaboration with healthcare providers, people living with HIV, and key affected populations.
- Allocate funding.
- Set targets and measure progress by institutionalizing routine measurement of stigma and discrimination to support (1) monitoring, (2) continual program improvement and enforcement of policies, and (3) the collection of data to facilitate the costing of programs for inclusion in budgets.
- Highlight the importance of S&D reduction to all sectors.

Health facilities and facility staff

- Develop and implement operational policies and practices at the healthcare facility level, as recommended in the framework, to ensure that the environment supports staff to provide non-stigmatizing and non-discriminatory care. This includes addressing both individual and facility-level actionable drivers of S&D.

- Set facility-level targets and monitoring through measurement: (1) the actionable drivers and manifestations of stigma and discrimination among facility staff ; (2) secondary stigma and discrimination that staff may experience because they care for people living with HIV; and (3) primary stigma that staff living with HIV may face within the facility.
- Ensure job protection for staff living with HIV.
- Build opportunities for feedback from and interactions with clients outside the provider-patient environment.

Medical training schools and medical associations

- Develop and incorporate stigma and discrimination reduction into pre- and in-service training curriculum for all levels of healthcare providers.
- Accredite facilities based on compliance with policies and progress toward becoming a facility free of stigma and discrimination, and recognize and reward progress.
- Certify staff who complete S&D reduction training.

Civil society

- Strengthen the capacity of civil society organizations and networks to understand HIV and intersecting stigmas and to access tools and approaches to reduce stigma and discrimination.
- Advocate for the institutionalization and scale-up of reduction of stigma and discrimination in health facilities.
- Monitor national- and facility-level commitments to stigma and discrimination reduction and hold governments and facilities accountable.
- Seek opportunities for partnership with health facilities to operationalize policies and programs on S&D reduction in facilities.

Researchers

- Study HIV-related stigma and discrimination as a key structural factor affecting access to and use of prevention, including treatment as prevention.
- Design and carry out studies that examine stigma and discrimination reduction as a key strategy for combination prevention.
- Include measurement of stigma and discrimination in clinical studies that aim to improve access, uptake, and adherence to care and treatment to analyze the relationship of S&D to key outcomes.
- Conduct policy and systems research to examine whether policies aimed at reducing stigma and discrimination are being implemented and having their intended effect.
- Examine stigma and discrimination as a factor affecting human resources for health.
- Carry out costing and cost-effectiveness studies on S&D reduction programs.

Donors

- Fund institutionalization, integration, and scale-up of stigma and discrimination reduction in health systems:
 - Set and measure specific global targets for reduction of stigma and discrimination in health facilities and track achievement in meeting them.
 - Support capacity strengthening in national programs to operationalize scale-up of S&D reduction in the health system.
 - Review funding proposals through a stigma reduction lens and advocate for inclusion of S&D reduction programming where appropriate, yet missing.
 - Routinely include measures of stigma and discrimination as required evaluation indicators of grantee progress.
- Support development of standardized measures for HIV-related stigma and discrimination in healthcare facilities. To have global standardized measures, indicators will need to be agreed on and approved by the UNAIDS Monitoring and Evaluation Reference Group. These measures should (1) capture both the drivers and manifestations of stigma and discrimination; (2) measure both individual- and institutional-level drivers; and (3) assess secondary stigma experienced by providers.

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