

1. BACKGROUND

SECTION 1.1: RATIONALE

Stigma and discrimination pose critical obstacles to stemming the HIV/AIDS epidemic. Increasingly, programs are addressing this problem, and it is thus essential to monitor and evaluate those efforts. There are currently no standard indicators to measure stigma and discrimination in developing-country contexts. As a part of its guidance to measure the effectiveness of an expanded response to the HIV/AIDS epidemic, the United States Agency for International Development (USAID) pressed for stigma indicators to be included as core indicators. The USAID Stigma and Discrimination Indicator Working Group (S&DIWG) was formed to address this gap, and, more specifically, to contribute to the monitoring and evaluation of USAID's expanded response to the HIV/AIDS epidemic. Based on the best suggestions from program experts and researchers grappling with stigma at the time, members of the S&DIWG proposed a set of indicators for the USAID expanded response in May 2002. These proposed indicators were subsequently included in the January 2003 edition of USAID's *Expanded Response Guide to Core Indicators for Monitoring and Reporting on HIV/AIDS Programs* (commonly referred to as the "Blue Book"). In February 2004, the S&DIWG reviewed these indicators in a daylong workshop with experts working in the arena of stigma and issued a series of recommendations to make the indicators more specific and measurable. While these efforts, particularly the February 2004 revised indicators, represent improvements in stigma indicators, they remained untested until now.

The demand for stigma indicators has continued to increase, particularly from USAID global missions and their partner agencies. Implementing agencies and donors need tested indicators by which they can reliably assess stigma in a given setting and measure progress in reducing it. In response to this need, USAID funded this first step, i.e., *field-testing and validation of an initial set of stigma indicators* at one site in Tanzania. This project builds expressly on the findings of the International Center for Research on Women (ICRW) and its partners in a multi-country study on stigma (Nyblade et al. 2003), and on the Horizons and POLICY Project work on stigma. The specific aim of this project is to examine, test, and validate selected stigma indicators from the Blue Book and the 2004 S&DIWG workshop. The results of this effort are found in this working report.

SECTION 1.2: PARTNERS

This study was conducted by a core group of S&DIWG members and their institutions. This activity was specifically implemented by ICRW, The Synergy Project/Social & Scientific Systems, Inc., and the Department of Psychiatry at Muhimbili University College of the Health Sciences (MUCHS) in Tanzania, with technical support from MEASURE Evaluation/Tulane University. The larger membership of the S&DIWG, in particular the Horizons Program, The POLICY Project, and USAID, served as an advisory group.

SECTION 1.3: DEFINITIONS

The standard point of departure for defining stigma is Erving Goffman's classic study on stigma related to mental illness, physical deformities, and what were perceived to be socially deviant behaviors (Goffman 1963). Goffman describes stigma as "an attribute that is deeply

discrediting” and results in the reduction of a person or group “from a whole and usual person to a tainted, discounted one.” He goes on to note that by regarding “others” negatively, an individual or group confirms its own “normalcy” and legitimizes its devaluation of the “other.”

Expanding on Goffman’s work, Link and Phelan describe stigma as a dynamic process occurring within the context of power (2001). This process has four distinct steps. The first three steps seek to divide the “tainted” from the “usual” people by distinguishing and labeling differences, associating negative attributes with those differences, and separating “us” from “them.” Gilmore and Sommerville describe these three steps in the process as allowing the others (“them”) to be perceived as non-persons (1994). This allows the “us” to distance themselves from the negative attributes of the “others,” to justify treating the “others” in negative ways that would be unacceptable if they were one of “us,” and to prevent “us” from being treated in the same negative manner. These steps culminate in the fourth and final step in Link and Phelan’s process—status loss and discrimination for the stigmatized. Thus, the ultimate effect of stigma, as noted by Goffman, is the reduction of the life chances of the stigmatized through discriminatory actions (1963).

In keeping with Goffman, and Link and Phelan, therefore, we do not conceptualize discrimination as separate from stigma, but as the end result of the process of stigma—in effect, “enacted” stigma. We define discrimination (or enacted stigma) as the negative acts that result from stigma and that serve to devalue and reduce the life chances of the stigmatized. A somewhat different definition of the word discrimination may be used by the legal or human rights communities in their work on HIV-related discrimination (Carael et al. 2000).

Goffman notes that the stigmatized often accept the norms and values that label them as having negative differences (1963). As a result, stigmatized individuals or groups may accept that they “deserve” to be treated poorly and unequally, making resistance to stigma and resulting discrimination even more difficult. This phenomenon is often termed “internalized stigma” (also sometimes termed “self-stigma”). Research shows that this internal stigma manifests in many ways, including self-hatred, self-isolation, and shame (Crandall 1991; Alonzo and Reynolds 1995; Lee et al. 2002). Compound stigma (also referred to as multiple stigma) is HIV stigma that is layered on top of preexisting stigmas, frequently toward homosexuals, commercial sex workers, injecting drug users, women, and youth (Herek and Capitano 1993; Herek et al. 2002; Boer and Emons 2004; Brown et al. 2004; Kalichman and Simbayi 2004; Nyblade 2004).

SECTION 1.4: STIGMA’S MAIN DOMAINS

Based on existing work, especially that of ICRW and its partners, Horizons, The POLICY Project, and other participants in the S&DIWG’s February 2004 meeting, the following domains were selected as the key areas for which indicators (and accompanying questions) are needed to enable comprehensive measure of stigma.

- Fear of casual transmission and refusal of casual contact with people living with HIV/AIDS (PLHA)
- Values: shame, blame, and judgment
- Enacted stigma (discrimination)
- Disclosure

From existing work, it is clear that there are two essential “causes” of HIV stigma: the continued fear of casual transmission, which stems in large part from a lack of depth in knowledge; and the moral dimension of stigma that justifies stigma through judgment, shame, and blame (Nyblade et al. 2003). These two domains indicate what programs will need to change if reduction of stigma is desired. Having a separate measure for each domain is necessary to determine if programs have more success in changing one domain than other. A composite measure, on the other hand, may lead to faulty conclusions about what is or is not happening as a result of a specific program. For example, if a program is working to reduce stigma by improving knowledge of transmission and reducing fear of casual transmission, but is not working to change the other key underlying cause—values shame, blame, and judgment—a composite measure of stigma may indicate that the program is having little impact on stigma overall, when, in fact, it is having impact on the portion of stigma that is driven by fear. However, use of more detailed indicators may signal whether the program has an impact on the one domain of stigma that it is trying to change, rather than the other.

In addition to these two domains, disclosure is an important area to measure, because it is a critical link between stigma and its negative effects on programs. Stigma impedes disclosure, which in turn affects prevention, care, support, and treatment. The extent of disclosure is often thought to be a good proxy measure for stigma or a measure of the “stigma” climate. Enacted stigma (discrimination) is very critical, yet thus far we have had no measures for it at the population level and very little measurement of it among PLHA.

SECTION 1.5: EXISTING MEASURES OF STIGMA

The largest problem with measuring stigma and discrimination in the developing-country context is the fact that there are very few tested and validated measures from which we can develop indicators. A review conducted as a part of this study identified a number of stigma measures that were commonly collected and also identified many gaps (Nyblade 2004).

The review revealed that most studies of stigma in the general population measured HIV/AIDS knowledge through questions on modes of transmission (correct and incorrect), prevention, and, in some cases, disease progression (Herek and Capitanio 1993; Herek et al. 2002; Boer and Emons 2004; Brown et al. 2004; Kalichman and Simbayi 2004). These studies also included some form of an indirect question to measure fear of casual transmission of HIV.

Studies that examined responsibility and blame¹ assessed the degree to which respondents felt that PLHA were responsible for contracting HIV and, therefore, had themselves to blame for being infected. Typical questions in the shame domain assessed agreement with statements such as “PLHA should be ashamed of themselves.” A few studies also included items on guilt. A related construct that was sometimes included is the belief that PLHA are being punished by God for their sins (Blendon and Donelan 1988; Dubbert et al. 1994; Crandall and Moriarty 1995; Fawole et al. 1999; Fife and Wright 2000; Boer and Emons 2004).

¹ Sometimes referred to as *victim blaming*

Other studies among the general population sought to measure negative feelings or emotional reactions to PLHA. Those that went beyond emotional reactions to behaviors assessed respondents' willingness to interact with PLHA. This was done most commonly, however, through hypothetical questions. Finally, some studies examined respondents' support for coercive measures toward PLHA such as quarantine, denial of entry into a country, mandatory reporting of status, and routine or regular testing of people at risk for contracting HIV (Snell et al. 1991; Herek and Capitanio 1993; Porter 1993; Green 1995; Johnson 1995; Herek and Capitanio 1997; Herek et al. 2002; Boer and Emons 2004; Kalichman and Simbayi 2004; Morrison 2004).

Studies assessing stigma related to PLHA fall broadly into three main categories of measurement: perceived stigma; experienced stigma; and internalized stigma. Measurement of internalized stigma, the last category, focused on how external stigma led to internal stigma in the form of negative self-image. In the first category, studies assessed how PLHA respondents perceive their partners, friends, family, and community might react to PLHA (Berger et al. 2001; Derlega et al. 2002; Clark et al. 2003; Preston et al. 2004; Swendeman et al. 2004). These studies either inquired about perceptions of attitudes—what others would think, or how supportive or unsupportive they would be of a person with HIV—or fear of behaviors—what PLHA thought would happen if others knew about the respondent's HIV status. Examples include losing friends, family rejection, being blamed, being avoided, or others¹ being uncomfortable around the respondent.

Only a few studies were found that had quantitative measures of the actual stigma PLHA experienced (Fife and Wright 2000; Berger et al. 2001; Asia Pacific Network of People Living With HIV/AIDS 2004; Swendeman et al. 2004). These studies measured enacted stigma (discrimination) in the form of denial of rights to health, education, and employment. They also measured exclusion by family and community (e.g., a person's refusal to eat with the respondent, or keeping children away from the respondent), loss of respect, and physical and verbal abuse or violence (e.g., ridicule toward the respondent, harassment, threats of violence, or assaults).

SECTION 1.6: CHALLENGES TO MEASURING STIGMA INDICATORS

Key challenges remain for any effort to measure stigma. An overarching challenge to measuring HIV stigma, especially relevant to evaluating whether programs and policies reduce stigma over time, is measuring an increase in HIV stigma that is not necessarily a 'true' increase, but rather a reporting increase due to improved awareness and recognition of HIV stigma. Other common challenges are:

- Sample selectivity and bias (particularly with studies among PLHA)
- Ambiguity of survey questions, and the meaning of indicators derived from them
- Collection of data about actual, rather than hypothetical, enacted stigma
- Refinement of existing measures at the general-population level

- Covering of all key domains of stigma, and expanding the contexts from which HIV stigma data is collected

The main challenge for measuring stigma among PLHA is sample selectivity. The only way to ethically contact PLHA for a survey is with a request for participation through networks of PLHA, service organizations, and health care providers, which precludes the possibility of obtaining a random sample of all people living with HIV. As a result, any data collected from PLHA may present biased results, as the data will be from a very select group of PLHA. PLHA participating in any study will: (a) have to know they are HIV-positive; and (b) belong to an association or be in search of social or health services from selected organizations that necessitates some level of public disclosure of HIV status. Those who fear or have experienced the most HIV stigma may be the least likely to have been tested or, if tested and positive, to participate in a group or seek services. Because this study also recruited PLHA respondents via networks of PLHA, it too suffers from this limitation.

Current measures of stigma focusing on HIV/AIDS knowledge, fear of casual transmission, or social distancing often suffer from ambiguity and the inability to specify the underlying cause (motive) for the action. Furthermore, many of the questions present hypothetical situations that may not accurately reflect how people might really act in a given situation. Consider the typical question, “Would you be willing to share food with a person with HIV/AIDS?” Ambiguity arises from the use of the words “share food,” as we do not know how the respondent interprets this term. Does it mean sitting at the same table, eating from the same plate, using utensils that might have been used by a PLHA, or perhaps even eating food the PLHA has prepared?

The interpretation often given to such a question is that a negative response indicates the presence of stigma driven by inadequate knowledge and/or fear of casual transmission of HIV. Yet, while this is a plausible explanation, we cannot know for sure. Partaking of food or drink together, whether in the home, bar, or tea/coffee house, is an important social activity in many cultures. Refusing to eat with a PLHA may not necessarily be about fear of casual transmission of HIV, but may be instead a form of social censure because the person is assumed to have contracted HIV through “immoral behavior.” Understanding the specific reason a person engages in a particular stigmatizing behavior is especially critical to developing effective programs to reduce stigma and may signal a different programmatic approach, depending on whether the cause is fear of casual transmission or negative judgments about PLHA. This study responds to the challenge of ambiguity in wording and underlying motives by refining the wording of questions, asking similar questions in different ways, and asking open-ended, follow-up *why* questions.

No studies attempting to measure actual occurrences of enacted stigma at the general population were found in the literature review conducted by Nyblade (Nyblade 2004). This is not surprising given the inherent challenges in doing this. The very presence of stigma means that asking any survey questions about a respondent's HIV status is unethical, removing the possibility of asking respondents whether they themselves have experienced HIV stigma, except for in surveys with PLHA. Additionally, a direct question asking the respondent if they themselves have engaged in stigmatizing behavior toward someone else is likely to suffer from a socially desirable, as opposed to truthful, response, particularly as programs to reduce stigma grow and more people become aware of stigma as inappropriate

or socially undesirable behavior. This is also the case for hypothetical questions about stigma. While it is not surprising that there are no studies measuring enacted stigma at the general population level, the same review found surprisingly few that measure the actual experience of stigma among PLHA (Fife and Wright 2000; Berger et al. 2001; Asia Pacific Network of People Living With HIV/AIDS 2004; Swendeman et al. 2004). This study seeks to overcome this gap by investigating the occurrence of enacted stigma among three population groups: general community members, PLHA, and health care providers.

A recent study of the causes, forms, and consequences of HIV stigma in Africa untangled the complexities of stigma and identified discrete domains (Nyblade et al. 2003). Most studies of stigma measure only one or a few domains of stigma and not all of them. In addition, the more comprehensive studies reviewed by Nyblade were usually conducted in small samples, or with very narrow groups of respondents (e.g., undergraduate students in the United States), while studies with larger, more representative samples only asked a few, often ambiguous, questions related to stigma (Nyblade 2004). Two aspects of HIV stigma stand out as lacking measurement at the population level: enacted stigma and compound stigma (HIV stigma that is layered on top of pre-existing stigmas, frequently toward homosexuals, commercial sex workers, injecting drug users, women, and youth). This study undertakes a far more comprehensive investigation of stigma by including indicators in numerous domains among a broad sample of the general population and two specific populations (PLHA and health care providers).

2. METHODS

As described in the previous section, HIV-related stigma is a complex construct with multiple dimensions. Therefore, a set of items or questions (as opposed to a single one) is tested to try to capture the complexity of each key dimension. Based on the existing literature and data, we measured items in four key domains: fear of casual transmission and avoidance of casual contact with PLHA; values and attitudes, including shame, blame, and judgment; the experience of stigma and discrimination (enacted stigma); and disclosure of HIV status. The first two domains are latent, or not directly observable, while the last two are manifest or observable.

Scales were developed and tested to measure the two latent domains, while an index and single-item indicators were tested for the manifest domains. Developing scales or indices is important when a single item or question may not capture the complexity of the phenomena. A scale composed of several items offers greater validity and precision when measuring an underlying, unobservable, or latent construct. Where we cannot measure the construct directly (e.g., stigma due to attitudes and values), we assess the relationships between a set of items that we believe reflect the latent or unobservable variable, such as responses to a series of attitudinal or value statements that we expect reflect HIV-related stigma (Spector 1992; DeVellis 2003; Netemeyer et al. 2003).

The complexity of stigma also indicates the need to develop indicators to measure stigma with specific groups. While some indicators may work across multiple sub-groups of the population, others will be critical to only one or a few groups, or will need to be measured in different ways for different groups. For example, although enacted stigma is an important indicator across all groups within a population, it will be measured differently among PLHA