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CAN WE MEASURE HIV/AIDS-RELATED STIGMA AND DISCRIMINATION?

CURRENT KNOWLEDGE ABOUT QUANTIFYING STIGMA IN DEVELOPING COUNTRIES

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1. INTRODUCTION

HIV-related stigma and discrimination (S&D) has accompanied the AIDS epidemic from the start. Fear of and actual experience with stigma and discrimination reduce an individual's willingness to practice prevention, seek HIV testing, disclose his or her HIV status to others, ask for (or give) care and support, and begin and adhere to treatment. As efforts to address S&D increase, so does the need for a set of standard tested and validated S&D indicators. Yet measures that can both describe an existing environment, and evaluate and compare interventions, are lacking. [1]

This report suggests ways to begin the process of quantitatively measuring HIV-related stigma in an effort to help practitioners, policymakers and donors evaluate their programs. The findings from a study in Tanzania that tested a number of potential quantitative measures for stigma provide the basis for much of the data presented here, including all recommendations for indicators and the questions that accompany each (Tables 1-4) (Tanzania stigma-indicators field testing group, 2005). [2] The report also includes questions that were used in other studies in an effort to quantitatively measure HIV stigma. These questions, which were obtained through a review of published literature and from responses to a request sent to several HIV listservs for unpublished studies, are listed in Appendices A-E to demonstrate the wide range of questions being used to measure stigma. Appendices A-D also suggest indicators under which the questions might fall. The questions are organized by domain and by the population for which they were asked.

Section 2 provides background on the need for quantitative measures of stigma and recent efforts to devise these. In section 3, HIV stigma indicators are organized around four key domains: (1) fear of casual transmission and refusal of contact with people living with HIV and AIDS; (2) values (shame, blame and judgment); (3) enacted stigma (discrimination); and (4) disclosure. These domains are based on the existing body of HIV S&D knowledge and help provide a comprehensive measure of HIV S&D (Tanzania stigma-indicators field testing group, 2005). For each domain, recommended indicators and accompanying questions are presented and segmented into three populations: community, health care workers and people living with HIV/AIDS. For each domain, limitations are presented first, followed by promising measures and recommended indicators.

The concluding section underscores the challenges and gaps that remain in measuring stigma and suggests next steps in the process of developing a comprehensive and standard set of indicators.

Stigma is "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" (Goffman, 1963). Thus, the ultimate effect of stigma, as noted by Goffman, is the reduction of the life chances of the stigmatized through discriminatory actions.

In keeping with Goffman, 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 and relevant laws and policies (Carael et al., 2000).

2. BACKGROUND

In 2002 the U.S. Agency for International Development (USAID) convened a small group of experts (SDIWG, Stigma and Discrimination Indicators Working Group) to begin a process of developing and testing indicators. Based on the best information available at that time, this working group[3] proposed a preliminary set of indicators that were included in the January 2003 edition of USAID's *Expanded Response Guide to Core Indicators for Monitoring and Reporting on HIV/AIDS programs.*

In February 2004, SDIWG convened a one-day meeting of a larger group of U.S.-based experts working on S&D to make the preliminary set of indicators more specific and measurable. USAID then commissioned a study in Tanzania (implemented by the International Center for Research on Women [ICRW], Muhimbili University College of the Health Sciences [MUCHS], and the Synergy Project) to test and validate this refined set of indicators.

The expanded working group met a second time in June 2005 to share individual members' current work on S&D, review the Tanzania field-test results and discuss the goal of standardizing stigma indicators across diverse settings.

Other efforts to establish a standard set of stigma indicators also are underway. The Royal Tropical Institute (KIT), in collaboration with the Swiss Tropical Institute and the London School of Hygiene & Tropical Medicine,[4] hosted a research workshop in 2004 on Health-related Stigma and Discrimination, which led to the establishment of the International Consortium for Research and Action on health-related stigma (ICRAAS). A key goal of this group is to develop standardized measurements of stigma across stigmatized health conditions, including HIV. In 2004 and 2005, UNAIDS and International Planned Parenthood Federation evaluated available indicators for a "PLHA Rights Index" to assess stigma experienced by people living with HIV and AIDS (PLHA).

While these efforts are a good start, more is needed as programs continue to develop and apply their own measures—or none at all—as stigma-reduction activities increase. To measure the impact of stigma-reduction programs, a comprehensive, standardized and streamlined set of indicators is needed that can feasibly be collected in the context of limited resources.

WHY MEASURE STIGMA?

- **Evaluate anti-stigma interventions.** Using reliable, quantitative measures over the course of an intervention will help determine if the intervention is as effective as it is perceived to be; identify aspects of stigma most responsive to the intervention activities; and suggest what modifications are needed.
- **Identify effective models and taking them to scale.** Program evaluations using quantitative measures will help program managers, donors and HIV/AIDS policymakers identify which anti-stigma approaches are most likely to be successful and how they should be applied in different contexts and among different populations. Anti-stigma interventions provide an opportunity to build a base of knowledge, but only if accompanied by evaluation data.
- **Compare HIV stigma across contexts.** Measures across the four domains described in this report provide a useful framework for assessing levels of stigma in new contexts. Quantitative measures enrich data already gathered through qualitative analysis and facilitate comparisons across communities, nations and regions by acting as a "common currency" for describing stigma.
- **Determine whether new trends in services and availability of treatment reduce stigma.** It sometimes is posited that stigma would decline if antiretrovirals were more widely available. Quantitative measures give us a tool to test this hypothesis just as the availability of treatment options are rapidly increasing in some countries and new patterns in health services, care and support, and other HIV programs are emerging.
- **Detect if a program is having unintended consequences.** Program managers can use stigma measures to determine if an HIV or other program or policy is inadvertently exacerbating HIV stigma in the community or target group with which it works. Program managers can then determine whether an aspect of the program should be modified or if an anti-stigma component should be added to the program.

3. INDICATORS: CURRENT KNOWLEDGE

This section provides an overview of current efforts to quantitatively measure stigma for three populations (community, health care workers and people living with HIV/AIDS) in four key domains:

- Fear of casual transmission and refusal of contact with people living with HIV/AIDS (PLHA);
- Value- and morality-related attitudes—blame, judgment and shame;
- Enacted stigma (discrimination);
- Disclosure.

The first two domains of HIV stigma and discrimination often are targeted by stigma and discrimination-reduction interventions; the third covers the actual experience and observation of S&D; and the fourth covers disclosure of HIV status. The last domain often is viewed as a proxy measure for S&D: where disclosure is widespread, it is generally assumed that S&D is not prevalent.

Other aspects of S&D—including anti-discrimination laws and policies, internal (self) stigma, and compound stigma and discrimination—are important but beyond the scope of this report.

Collecting data across multiple domains is particularly critical in evaluating the effect of interventions on stigma. Therefore, we recommend that at least one indicator be used in each of the four main domains of stigma used in this report.

3.1 FEAR OF CASUAL TRANSMISSION AND REFUSAL OF CONTACT WITH PEOPLE LIVING WITH HIV/AIDS

Fear of casual transmission and refusal of contact with people living with HIV/AIDS has been the principal domain where surveys have attempted to measure stigma. The label of this domain reflects both the direct underlying cause of stigma (fear of HIV transmission) and the resulting stigmatizing action (refusal of contact with people living with HIV/AIDS).

QUANTITATIVE MEASURES WITH LIMITATIONS

Most attempts to measure this domain involve hypothetical questions about a respondent's willingness to interact with a person with HIV/AIDS, such as sharing a meal, buying food, or caring for him or her (see Appendix A for examples of questions for this domain). The underlying assumption is that refusal of contact is an indication of S&D driven by fear of transmission through such contact. However, such questions have several limitations:

- They are hypothetical;
- They may suffer from bias due to the possibility of respondents providing responses that are socially acceptable rather than correct (social desirability bias);
- Because the questions are ambiguous, the respondent could interpret them in several ways, rendering them invalid for obtaining a standard measure; and
- They do not capture the underlying cause of the resulting behavior.

For all the above reasons, the use of such indicators remains problematic.

PROMISING QUANTITATIVE MEASURES

Table 1 presents two indicators recommended for the community level and four indicators for health providers, with accompanying questions. Of these, the key recommended indicator for this domain, particularly at the community level, is the first one, which measures the actual fears that individuals hold about transmission of HIV through noninvasive routes (i.e., no exchange of body fluids).

The Tanzania study tested and validated a wide range of indicator-related items for actual fears of both community and health providers (Tanzania stigma-indicators field testing group, 2005). Only those items that the study recommended are presented here. The first indicator is recommended because it measures an actual fear (as opposed to hypothetical action), and the responses given to questions under this indicator also highlight specific fears, providing valuable information for programs trying to address stigma. Similar items were included in studies in South Africa (B. M. Brown, 2004) and Brazil (Pulerwitz et al., 2004).

TABLE 1:
RECOMMENDED INDICATORS, QUESTIONS FOR FEAR OF CASUAL CONTACT WITH PEOPLE LIVING WITH HIV/AIDS

	INDICATOR	**DATA COLLECTION QUESTIONS**
Community-level	Percent of people expressing fear of contracting HIV from noninvasive contact with PLHA.	Please tell me if you have fear, do not have fear, or do not know in response to the following statements: 1. You could become infected with HIV if you are exposed to the saliva of a PLHA. 2.. You could become infected with HIV if you are exposed to the sweat of a PLHA. 3. You could become infected with HIV if you are exposed to the excreta of a PLHA. 4. Your child could become infected with HIV if they play with a child who has HIV or AIDS. 5. You could become infected if you care for a PLHA.
	Percent of people who would refuse casual contact with a PLHA who: a) was not exhibiting signs of AIDS. b) was exhibiting signs of AIDS.	In a market of several food vendors, would you buy food from a PLHA or person suspected of HIV/AIDS who was not visibly sick? And what if they were visibly sick?
Provider-level	Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear contact with non-blood bodily fluids of patients with HIV/AIDS.	In response to the following situations, please indicate if you have fear of HIV transmission, do not have fear of HIV transmission, or do not know if you have fear of HIV transmission: 1. Touching the sweat of a person with HIV or AIDS. 2. Touching the saliva of a person with HIV or AIDS.
	Percent of people working in institutions/facilities (e.g., managers, health care workers) who fear providing invasive medical care for patients with HIV/AIDS.	In response to the following situations, please indicate if you have fear of HIV transmission, do not have fear of HIV transmission, or do not know if you have fear of HIV transmission: 1. Giving an injection to a person with HIV or AIDS. 2. Caring for a person with HIV or AIDS. 3. Dressing the wounds of a person with HIV or AIDS. 4. Conducting surgery on or suturing a person with HIV or AIDS. 5. Putting a drip in someone who is showing signs of AIDS.
	Percent of people working in institutions/facilities (e.g., managers, health care workers) who are uncomfortable working with or treating PLHA.	Do you strongly agree, agree, disagree or strongly disagree with each statement: 1. I am comfortable assisting or being assisted by a colleague who is HIV infected. 2. I am comfortable performing surgical or invasive procedures on clients whose HIV status is unknown. 3. I am comfortable providing health services to clients who are HIV-positive. 4. I am comfortable sharing a bathroom with a colleague who is HIV-infected. 5. Clients who are sex workers deserve to receive the same level and quality of health care as other clients. 6. You avoid touching the clothing and belongings of clients known or suspected to have HIV for fear of becoming HIV-infected.
	Percent of people working in institutions/facilities (e.g., managers, health care workers) who perceive work-related HIV exposure to be high.	Do you strongly agree, agree, disagree or strongly disagree with each statement: 1. The most frequent mode of contracting HIV among health care workers is through work-related exposure. 2. Most HIV-positive health care workers get infected at work.

The second community-level indicator in Table 1 attempts to capture behavior that results from fear of casual transmission. It measures the behavior of refusing contact with a person living with HIV/AIDS, with one key improvement: The wording of the questions used to inform this indicator connects the action (refusal of contact) with fear of transmission. In the Tanzania field study, a range of often-used questions about stigmatizing behavior, assumed to result from fear, were tested and most items performed poorly on the criteria of variability; the best question that emerged was about buying food from a market vendor (Tanzania stigma-indicators field testing group, 2005).

Two caveats are necessary here. First, the response to these types of questions can vary substantially depending on whether the question specifies if the vendor has physical signs of AIDS (Yoder & Nyblade, 2004). Variation also may occur depending on whether the food is raw or cooked, and how it is wrapped and handled. Therefore, we recommend that any such question have two parts to it (see Table 1).

REMAINING GAPS

Further testing of these promising indicators should be conducted in other settings. Such testing could determine the best set of questions to capture fears across settings and ensure that respondents understand that the questions refer to noninvasive contact where body fluid is not exchanged. There is also a need to develop questions that capture fears around noninvasive contact with blood, for example dried blood left on hair or nail-cutting scissors (Tanzania stigma-indicators field testing group, 2005). In addition, further studies should explore fears people living with HIV hold about casually infecting others (e.g., through daily contact with their children).

3.2 VALUES: SHAME, BLAME AND JUDGMENT

A second, equally important causal domain of S&D for measurement is moral- or value-driven stigma where assumptions and judgments are made about how people living with HIV/AIDS contract HIV, which are manifested in stigmatizing attitudes (Ogden & Nyblade, 2005; Policy Project, 2003; Pulerwitz et al., 2004). Recent studies confirm that at least three key dimensions are important to measure in this domain: shame, blame and judgment (Ogden & Nyblade, 2005; Policy Project, 2003; Pulerwitz et al., 2004; Tanzania stigma-indicators field testing group, 2005).

QUANTITATIVE MEASURES WITH LIMITATIONS

This domain, despite being shown as a critical driver of HIV stigma in descriptive studies (Banteyerga et al., 2004; Bond et al., 2003; Mbwambo et al., 2004; Nyblade et al., 2003; Ogden & Nyblade, 2005), has not been measured frequently. As such, the main limitation for this domain is a lack of tested indicators. The Tanzania study tested both positively and negatively framed questions and found that questions framed in the positive (e.g., I "would" attend a social event with someone known to have HIV) showed little variability.

PROMISING QUANTITATIVE MEASURES

Table 2 presents the recommended community and health provider indicators for this domain, along with the questions for each indicator. The results from Tanzania suggest two indicators for use with community samples (the first combines blame and judgment) and three indicators for health providers. Each of the items performed satisfactorily on tests of reliability and validity.

The sensitive nature of these attitudinal statements means that respondents may provide socially acceptable answers, which would lead to underreporting of value-driven stigma. To explore this possibility, the items were asked in two ways in the Tanzania study: (1) respondents were asked about their own response to each statement, and (2) later in the questionnaire they were asked about their perception of how the majority of their community would answer these same statements. For all statements, respondents indicated a much higher level of perceived stigma in their community relative to their own responses (Tanzania stigma-indicators field test group, 2005). While the study could not determine whether this difference was due to social desirability bias or a genuine difference between respondents' self-reported stigmatizing attitudes and perceptions about the level of stigma in the community, given the large difference, it is prudent to ask about this domain in both ways.

REMAINING GAPS

Given the challenges described above, questions in this domain need refinement. In particular, the wording of these items needs further testing, and attitudinal statements that clearly measure HIV-stigma and work equally well across multiple and diverse contexts need to be further developed.[5] In addition, future studies should explore attitudes of people living with HIV and AIDS toward each other.

3.3 ENACTED STIGMA (DISCRIMINATION)

We use the term *enacted stigma* here, rather than *discrimination*, to capture a wider set of actions than typically are associated with discrimination. Discrimination often is understood to mean *unlawful* acts of exclusion, or abuse that occurs in formal institutional settings (such as dismissal from employment or refusal of health care). The broader term used here is meant to include important stigmatizing actions that are not usually captured under the term discrimination, such as gossip, social or physical isolation, or loss of business clientele due to one's HIV status.

QUANTITATIVE MEASURES WITH LIMITATIONS

When conducting a general survey of people whose HIV status is unknown, it is not appropriate to ask respondents if they themselves have experienced HIV-related stigma because that would require them to disclose their HIV status. In addition, asking respondents if they have committed specific acts of stigma may lead to underreporting, particularly as anti-stigma programming grows and individuals become aware that it is not "socially desirable" to stigmatize. These have been the main obstacles to obtaining quantitative measures of enacted stigma among these populations, with the end result that studies seldom include such direct measures.

PROMISING QUANTITATIVE MEASURES

Table 3 presents indicators and questions for all three populations. An indicator for observed enacted stigma, as opposed to *experienced* enacted stigma, was developed for use with community and health provider samples. The questions devised to inform this indicator were tailored to reduce rates of reporting about incidents reported in the media, or well-known in the community, by asking the respondents if they *personally* know anyone who has experienced a given form of HIV-related stigma in the past year. An indicator for *experienced* enacted stigma was tested among a sample of people living with HIV/AIDS.

In Tanzania, reliability tests were performed on a wide range of items to measure enacted stigma, shown in Appendix C. The items in bold indicate the minimum core group of items recommended from this analysis. These indicators performed well and showed good variability in response.

TABLE 2:
RECOMMENDED INDICATORS, QUESTIONS FOR VALUES (SHAME, BLAME AND JUDGMENT)

	INDICATOR	DATA COLLECTION QUESTIONS
Community-level	Percent of people who judge or blame persons living with HIV/AIDS for their illness.	Do you agree/disagree with the following statement: 1. HIV is a punishment from God. 2. HIV/AIDS is a punishment for bad behavior. 3. It is women prostitutes who spread HIV in the community. 4. People with HIV are promiscuous. How do you think most people in your community would answer the previous questions?
	Percent of people who would feel shame if they associated with a PLHA.	Do you agree/disagree with the following statement: 1. I would be ashamed if I were infected with HIV. 2. I would be ashamed if someone in my family had HIV/AIDS. 3. People with HIV should be ashamed of themselves. How do you think most people in your community would answer the previous questions?
Provider-level	Percent of people working in institutions/facilities (e.g., managers, health care workers) who report judgment.	Do you agree/disagree with the following statement: 1. HIV is a punishment from God. 2. HIV is punishment for bad behavior. 3. People with HIV should be ashamed of themselves.
	Percent of people working in institutions/facilities (e.g., managers, health care workers) who report blame.	Do you agree/disagree with the following statement: 1. Promiscuous men are the ones that spread HIV in our community. 2. It is the women prostitutes who spread HIV.
	Percent of people working in institutions/facilities (e.g., managers, health care workers) who report shame.	Do you agree/disagree with the following statement: 1. I would feel ashamed if I was infected with HIV. 2. I would feel ashamed if someone in my family was infected with HIV.

TABLE 3:
RECOMMENDED INDICATORS, QUESTIONS FOR ENACTED STIGMA (DISCRIMINATION)

	INDICATOR	**DATA COLLECTION QUESTIONS**
Community-level	Percent of people who personally know someone who has experienced enacted stigma in the past year because he or she was known or suspected to have HIV or AIDS.	Do you know someone in the past year who has had the following happen to him/her because of HIV or AIDS? 1. Excluded from a social gathering. 2. Lost customers to buy his/her produce/goods or lost a job. 3. Had property taken away. 4. Abandoned by spouse/partner. 5. Abandoned by family/sent away to the village. 6. Teased or sworn at. 7. Lost respect/standing within the family and/or community. 8. Gossiped about. 9. No longer visited, or visited less frequently by family and friends. 10. Visitors increase to "check them out." 11. Isolated within the household.
Provider-level	Percent of people in institutions/facilities (e.g., managers, health care workers) who personally know patients who were [fill in type of discrimination] in the past 12 months because they were known or suspected to have HIV/AIDS: neglected, treated differently, denied care, verbally abused, tested for HIV or had sero-status disclosed without consent.	In the past 12 months, have you seen or observed the following happen in this health facility because a client was known to have or was suspected of having HIV/AIDS? 1. Receiving less care/attention than other patients. 2. Extra precautions being taken in the sterilization of instruments used on HIV-positive patients. 3. Requiring some clients to be tested for HIV before scheduling surgery. 4. Using latex gloves for performing noninvasive exams on clients suspected of having HIV. 5. Because a patient is HIV-positive, a senior health care provider assigned the client to a junior provider. 6. Testing a client for HIV without his/her consent. 7. Health care providers gossiping about a client's HIV status.
PLHA-level	Percent of PLHA who experienced enacted stigma in last year.	In the last year, have you [fill in from list below] because of your HIV status? **1. Been excluded from a social gathering.*** **2. Been abandoned by your spouse/partner.** **3. Been isolated in your household.** **4. Been no longer visited or visited less frequently by family and friends.** **5. Been teased, insulted or sworn at.** **6. Lost customers to buy produce/goods or lost a job.** **7. Lost housing or not been able to rent housing.** **8. Been denied religious rites/services.** **9. Had property taken away.** **10. Been gossiped about.** **11. Lost respect/standing within the family and/or community.** **12. Been threatened with violence.** 13. Been given poorer quality health services. 14. Been physically assaulted. 15. Been denied promotion/further training. 16. Had an increase of visitors to "check out" how you are doing. 17. Been abandoned by your family/sent away to the village.

*Bolded items indicate the minimum core group of items recommended from this analysis

REMAINING GAPS

The indicators in this domain need to be tested in multiple contexts, and individual items need to be refined to capture the wording that will work best across settings. Some specific areas that warrant refinement include the form of stigma related to loss of identity and roles, and the issue of social and physical isolation.

In low prevalence settings, where most respondents are unlikely to personally know a person living with HIV, the questions on *observed* enacted stigma may need to be broader, simply asking if the respondent has heard of anyone who has experienced a specific form of stigma in the past year.

3.4 DISCLOSURE

Disclosure often is considered a proxy measure for S&D, with the assumption that where S&D is low, disclosure will occur more often and among a wider group of individuals. A simple indicator for disclosure may capture valuable information about stigma where a full set of items for the previously discussed domains is not feasible.

QUANTITATIVE MEASURES WITH LIMITATIONS

Direct measurement of this domain among the general population has been infrequent because often only a minority of respondents have been tested for HIV, and because of the debate over whether it is appropriate to ask direct questions about disclosure to a random sample of the population. Therefore, most measurement with populations of unknown HIV status has been limited to hypothetical questions (e.g., *If you had HIV, would you disclose your status?*) which show little variability (Tanzania stigma-indicators field testing group, 2005).

Another question attempting to capture the presence of stigma by using disclosure as a proxy—sometimes asked in Demographic Health Surveys (DHS)—has been of the nature: *"If a person learns he/she is infected with the virus that causes AIDS, should the person be allowed to keep this fact private or should this information be available to the community?"* The interpretation of the response to this question has been that where stigma is low, respondents will indicate that disclosure to the community is appropriate.

However, the Tanzania study found this interpretation to be misleading: The majority of respondents indicated that status should be available to the community, not because stigma was low, but so that the community could "protect" itself from the person. Because of this finding, and the difficulty of interpreting this question, the study did not recommend using this indirect disclosure question unless a follow-up "why" question is asked and the results analyzed and reported for both questions. Two other studies improved on this ambiguity by explicitly asking about disclosure in order for others to protect themselves [6] (Boer & Emons, 2004; B. M. Brown, 2004).

PROMISING QUANTITATIVE MEASURES

Table 4 presents the recommended indicators and related questions for the domain of disclosure for all three populations (community, health-care provider and people living with HIV/AIDS).

The data on people living with HIV/AIDS from the Tanzania field test indicate that the relevant information about disclosure, if it is to be a proxy measure for stigma, is: (1) to whom a person has disclosed their results, and (2) how long a period elapsed from learning status till disclosure.[7] Direct questions about disclosure are recommended, although both direct and indirect questions about disclosure specifically for people living with HIV/AIDS can be found in Table 4.

REMAINING GAPS

While disclosure is often thought of as a proxy measure for S&D, few studies at the population level have gone beyond asking hypothetical questions about disclosure of HIV status. The Tanzania field-test demonstrates that hypothetical questions, or even a direct general question (*have you disclosed?*), provide little useful information about disclosure in relation to S&D. Additional indirect questions are promising, but need to be tested further in different settings and analyzed in relation to the HIV-prevalence rates in the sample population.

TABLE 4:
RECOMMENDED INDICATORS, QUESTIONS FOR DISCLOSURE

	INDICATOR	DATA COLLECTION QUESTIONS
Community-level	Percent of people who have had someone they personally know disclose their HIV-positive status to them.	Are there people you personally know who have either disclosed their HIV-positive status directly to you or publicly in the last 12 months? For example, a family member, friend, neighbor, church member, work colleague?
	Percent of persons tested for HIV who have disclosed their status beyond a trusted few individuals.	How many people have you disclosed your status to? How soon after learning your HIV status did you disclose your status to these specific people?
	Percent of persons tested for HIV in relationship who have disclosed their status to their primary sexual partner and who have disclosed within 6 months of learning their status.	
	Percent of persons reporting that self-disclosure by PLHA is a primary way that people in the community find out about a person's HIV status.	In your community, what is the primary way people know if someone has HIV? 1. The infected person discloses his/her status. 2. From general rumors/gossip. 3. From the HIV-positive person's family. 4. From the HIV-positive person's employer. 5. From the HIV-positive person's friends/neighbors. 6. From the health center/health care worker where the person got tested. 7. The person looks ill and has lost a lot of weight. 8. Other (specify).
Provider-level	Percent of people working in institutions/facilities (e.g., managers, health care workers) who learned about a patient's HIV status through unofficial channels during the past year.[8]	Is there anyone you know in the health facility who has HIV, but has not yet shown signs and symptoms of AIDS? How did you know that he/she has HIV infection? Do you know of a health worker/colleague who has HIV or AIDS? How did you know he/she has HIV or AIDS? 1. The infected person told me her/himself. 2. Family member of infected person told me. 3. Community member told me. 4. General gossip/rumors. 5. From a health care provider where the person tested. 6. Read from his/her hospital file. 7. Other.
PLHA-level	Percentage of PLHA who have disclosed their status beyond a few trusted individuals and who have disclosed within 6 months of learning his/her status.	Have you told anyone about your HIV status? * Who have you told? How soon after learning your HIV status did you disclose your status to these specific people?
	Percentage of PLHA who have disclosed their HIV sero-status to their primary sexual partner.	Who have you told?
	Percent of PLHA whose HIV status has been disclosed without their consent.	Has your HIV status ever been revealed without your consent?

* It is not always considered ethical to ask if a person living with HIV has disclosed her or her HIV status. It is important to be aware of how that is perceived in each context.

4. THE WAY FORWARD: CONTINUING CHALLENGES AND REMAINING GAPS

This report lays out current knowledge and recommendations for quantitatively measuring S&D in a developing country context. Although recent work in the development of indicators has brought the international community closer to measuring stigma quantitatively, more work is needed to reach the goal of using quantitative measures to describe the state of S&D in any given setting with confidence and clarity or to draw comparisons across settings. In particular, the following next steps are needed: (1) capture stigma's multiple domains; (2) test the viability of a standard set of quantitative measures; (3) standardize and refine wording of data collection items; (4) design appropriate questions for surveys; and (5) develop indicators for understudied aspects of stigma.

CAPTURE STIGMA'S MULTIPLE DOMAINS

Stigma is a multi-faceted phenomenon. Measures in all of stigma's domains are needed to capture a full picture of the complexity of stigma. At a minimum, several indicators are needed for each domain.

TEST THE VIABILITY OF A STANDARD SET OF QUANTITATIVE MEASURES

Further testing would determine if a standardized set of quantitative measures accurately captures stigma and all its facets in multiple settings. We need to establish whether the same indicator and data collection items work equally well if settings differ according to:

- Prevalence;
- Knowledge of HIV and AIDS;
- Normative and value structures;
- Access to services and treatment options; and
- Official responses to the HIV epidemic.

While recent qualitative research indicates that stigma is similar in its forms, causes and consequences in settings ranging from Tanzania to Vietnam to Ethiopia and Zambia (Ogden & Nyblade, 2005), it is unknown whether these similarities will lead to the same indicators and questions working equally well across a range of contexts. It may be that the same overall indicators would work across varying contexts (e.g., cultural, socioeconomic, epidemic experience), but that the specific wording of the corresponding questions needs to be tailored to different social contexts.

STANDARDIZE AND REFINE WORDING OF DATA COLLECTION ITEMS

If S&D were routinely assessed by researchers and program implementers using the same, standard set of quantitative measures, we would be able to make comparisons among different settings and time periods. We also would be better able to compare programmatic approaches to reducing stigma or overcoming the obstacles stigma poses to HIV prevention, care, treatment and support programs and identify those approaches that show the most promise. In addition, a standardized set of measures might allow for the calculation of a summary measure such as a stigma index. This index, if possible to calculate, would be valuable in characterizing the state of stigma at larger scales and facilitate cross-country or regional comparisons.

DESIGN APPROPRIATE QUESTIONS FOR SURVEYS

We need to respond to the challenges of what can and cannot be asked on surveys of respondents of unknown status while simultaneously upholding high ethical standards. We should explore innovative ways to ask about experience, observation, and perpetuation of stigma and individual and community values that do not require disclosure of HIV status. In addition, we need to test further which data collection items are most necessary for each indicator to develop a minimum set of items for each indicator. The indicators also should be able to capture change as it occurs.

DEVELOP INDICATORS FOR UNDERSTUDIED ASPECTS OF STIGMA

Areas for which stigma indicators have not been sufficiently tested include:

- Internal (self) stigma;
- Laws and policies; and
- Compound (layered or multiple) stigma.

An initial foray into testing indicators for these areas was included in the Tanzania field test (Tanzania stigma-indicators field test group, 2005). Internal stigma is marked by acceptance of stigmatizing beliefs and actions; negative self-image (feelings of shame, self-blame and guilt); and abandonment of life aspirations, withdrawal, and self-isolation from relationships and activities. The field test concluded that a more comprehensive set of measures is needed for negative self-image and abandonment of life aspirations, while no measures have been developed for acceptance of stigma. At least one other study is exploring this issue in the Dominican Republic (Miric, 2004). Quantitative measures for policies and laws should capture whether people are aware of policies and laws dealing with HIV-related S&D, what they know and whether it is correct, and what systems are available for redress and whether and how they are used by those who experience S&D. Programs would benefit from measures for compound stigma to describe how HIV-related stigma is layered on other stigmas people living with HIV/AIDS may experience, and to tease out that part of stigma that is due to HIV. The POLICY project is conducting a study in Mexico exploring measures on aspects of compound stigma (Mo Kexteya, 2004).

ESTABLISH A KNOWLEDGE SHARING FORUM

Many people developing stigma measures or seeking to use stigma measures have expressed a need for a knowledge sharing forum. Such a forum would serve as a mechanism to collect information about stigma measurement, interventions and tools in one place. It would be a forum for interested professionals to share information and experiences, and learn from each other. Although the SDIWG seeks to serve this purpose, it is limited in scope, membership and funding, meaning that its longevity is not secured. A more permanent forum also would be more accessible to various professionals across the globe.

APPENDIX A:
SCAN OF QUESTIONS USED TO MEASURE FEAR OF CASUAL TRANSMISSION AND REFUSAL OF CONTACT WITH PEOPLE LIVING WITH HIV/AIDS, GROUPED BY INDICATOR

COMMUNITY-LEVEL

INDICATOR	QUESTIONS TO INFORM THE INDICATOR	SOURCE
Percent of people expressing fear of contracting HIV from noninvasive contact with people living with HIV/AIDS.	Please answer whether you agree or disagree with the following statements: 1. It is safe for people who have AIDS to work with children. 2. People who have HIV should be isolated.	(Kalichman et al., 2005) South Africa
	Please answer whether you agree or disagree with the following statements: 1. It is safe to let my child play with children who have HIV/AIDS. 2. A person who has AIDS should not be allowed to work to protect the people who don't have AIDS.	(Pulerwitz et al., 2004) Brazil
	Would you rather not touch someone with HIV/AIDS because you are scared of infection? Do you think that a school pupil with HIV puts other pupils in their class at risk of infection?	(B. M. Brown, 2004) South Africa
	Would you drink from the same bottle of water as an HIV-infected friend? If you knew a shopkeeper had HIV/AIDS, would you buy fresh vegetables from him or her?	(Brown et al., 2004)* Ghana, Kenya, Malawi, Uganda, Zambia, Zimbabwe (DHS); Benin, Burkina Faso, Cameroon, Ivory Coast, Niger (BSS)
Percent of people who would refuse casual contact with a person living with HIV or AIDS who (a) was not exhibiting signs of AIDS; (b) was exhibiting signs of AIDS.	If a relative of yours became sick with the virus that causes AIDS, would you be willing to care for her or him in your own household? (DHS, BSS) Can a person get the AIDS virus by sharing food with a person who has AIDS? (DHS) Would not share meal with HIV-positive person? (BSS) If you knew that a shopkeeper or food seller has the AIDS virus, would you buy food items from him/her? (DHS, BSS)	
	If a member of your family became sick with HIV/AIDS, would you be willing to care for him or her in your household? If you knew that a shopkeeper or a food-seller had HIV/AIDS, would you buy vegetables from him/her?	(Letamo, 2003) Botswana
	If a female relative of yours became sick with the virus that causes AIDS, would you be willing to care for her in your household?	(Banteyerga et al., 2004) Ethiopia
	Please answer whether you agree or disagree with the following statements: 1. You would eat at the same table as a person HIV/AIDS. 2. Your community would invite a person infected with HIV/AIDS to social occasions. 3. A man who has HIV/AIDS would be abandoned by his partner. 4. A woman who has HIV/AIDS would be abandoned by her partner.	(Banteyerga et al., 2004) Ethiopia (Pulerwitz, 2005) Nicaragua
	Please answer whether you agree or disagree with the following statements: 1. I would feel comfortable traveling with someone who has HIV/AIDS in my truck. 2. I would be willing to care for a relative with AIDS in my house. 3. I would feel comfortable getting a haircut from someone with HIV/AIDS. 4. I would worry about sharing a glass with someone who has HIV.	(Banteyerga et al., 2004) Ethiopia (Pulerwitz et al., 2004) Brazil (Pulerwitz, 2005) Nicaragua
	According to your personal opinion, please tell me if you are or are NOT in agreement with the following:** 1. A student with HIV should be allowed to continue going to school. 2. A pre-school or primary school teacher with HIV should continue teaching classes. 3. People living with HIV/AIDS should not have contact with other patients in a waiting room. 4. The diagnostic test for HIV should be voluntary. 5. I would buy food from a person who is living with HIV. 6. I would go to a dentist who has HIV. 7. I would go to a homosexual doctor. 8. Surgeons with HIV should be allowed to continue working. 9. I would share a house with a person who has HIV. 10. I would work with a colleague who has HIV. 11. It is necessary to carry out mandatory HIV tests on men who have sex with other men.	(Morrison, 2005) Mexico

*This report draws on data from two surveys: Demographic Survey [DHS] (Macro Int'l.) and Behavioral Surveillance Survey [BSS] (Family Health Int'l.).
** Questions asked only of health providers.

APPENDIX B:
SCAN OF QUESTIONS USED TO MEASURE SHAME AND BLAME, GROUPED BY INDICATOR

COMMUNITY-LEVEL

INDICATOR	QUESTIONS TO INFORM THE INDICATOR	SOURCE
Percent of people who judge or blame persons living with HIV/AIDS for their illness.	Do you think HIV/AIDS is a punishment for sleeping around? Do you think that many people who get HIV through sex have only themselves to blame?	(B. M. Brown, 2004) South Africa
	Please answer whether you agree or disagree with the following statements: 1. A person with AIDS must have done something wrong and deserves to be punished. 2. People who have AIDS are cursed.	(Kalichman et al., 2005) South Africa
	How likely or unlikely do you believe the following statements are: If someone has contracted HIV by unsafe sex, it is their own fault. If someone has contracted HIV by blood transfusion, it is their own fault.	(Boer & Emons, 2004) Thailand
	How much do you agree/disagree about the following statements: 1. People who got AIDS through sex or drug use have gotten what they deserve. 2. For most people with HIV, it is their own fault that they got HIV. 3. People with HIV/AIDS should be ashamed of themselves. 4. People with HIV/AIDS have nothing to feel guilty or ashamed about. 5. People with HIV/AIDS are blamed for bringing the disease into the community. 6. The family of the person with HIV/AIDS is also to blame. 7. The family is cursed and should be avoided and isolated. 8. People with HIV/AIDS are promiscuous. 9. Women get HIV because they are prostitutes. If a member of your family contracted HIV/AIDS, would you want it to remain a secret? If yes, why would you want it to remain a secret? 1. Family members would be blamed. 2. Family member would find it difficult to get access to care and treatment. 3. Family member would be neglected, isolated, avoided. 4. Family member would be verbally abused, teased. 5. Family member would be physically abused. 6. Family member would not be allowed to go to work/school. 7. Family member would not be allowed to go to church/mosque. 8. Family member would not be allowed to be in public places. 9. People would avoid the entire family. 10. People would blame the entire family. 11. People would stop interacting with the entire family. 12. Other (if other, specify).	(Banteyerga et al., 2004) Ethiopia
	Please answer whether you agree or disagree with the following statements: 1. AIDS is a punishment for bad behavior. 2. AIDS is a punishment from God. 3. Truckers are to blame for spreading HIV/AIDS. 4. Almost all people who have HIV/AIDS are gay men and prostitutes.	(Pulerwitz et al., 2004) Brazil

HEALTH PROVIDER-LEVEL

INDICATOR	QUESTIONS TO INFORM THE INDICATOR	SOURCE
Percent of people working in institutions/facilities (e.g., managers, health care workers) who report blame.	Do you agree/disagree with the following statement: HIV/AIDS spreads due to immoral behavior.	(Mahendra et al., 2005 India)
	According to your personal opinion, please tell me if you are or are NOT in agreement with the following: 1. Prostitution should be prohibited as a method of reducing the transmission of HIV. 2. Homosexuality is the cause of AIDS in Mexico.	(Morrison, 2005) Mexico

APPENDIX C:
SCAN OF QUESTIONS USED TO MEASURE ENACTED STIGMA, GROUPED BY INDICATOR

PEOPLE LIVING WITH HIV/AIDS-LEVEL

INDICATOR	QUESTIONS TO INFORM THE INDICATOR	SOURCE
Percentage of people living with HIV/AIDS who have experienced enacted stigma.	In what ways have you felt discriminated against (treated badly) by your family? They: 1. Don't visit me. 2. Don't touch me. 3. Don't eat with me. 4. Don't sit with me. 5. Deserted me. 6. Verbally abuse me. 7. Physically abuse me. 8. Hide me so no one knows I have HIV. In general, have you felt discriminated against (treated badly) by your community? In what ways have you felt discriminated against (treated badly) by your community? 1. Family was excluded in community events. 2. Your children were discriminated against in school. 3. Nobody played with my children. 4. Neighbors stopped visiting the house. 5. Neighbors told others about my HIV status. 6. Verbal abuse by the community. 7. Was asked to leave the community. 8. People stare at me and pass remarks. 9. Other.	(FHI, 2004) Nepal
	Have you ever [fill in from list below] because of your HIV status? 1. Had a health care worker refuse to treat you/denied access to medical treatment or care. 2. Experienced a delay in the provision of health services/treatment. 3. Been stopped from accessing health care services. 4. Forced to pay additional charges for medical services (e.g., dental care, surgery). 5. Ever lost or been denied private insurance. 6. Been forced to change your place of residence because you are known to be HIV-positive. 7. Been refused entry to, removed from or asked to leave a public establishment. 8. Been ridiculed, insulted or harassed. 9. Been threatened by physical violence. 10. Been quarantined, detained, isolated or segregated. 11. Had any benefits, privileges or services given to others been denied to you. 12. Been excluded from any social functions. 13. Had friends discriminate against you. 14. Been forcibly required to submit to any medical health procedure. 15. Been charged, sued or brought to court on an offence or an act. 16. Had your earning capacity decrease. 17. Experienced discrimination in your work environment. 18. Had your employer discriminate against you. 19. Felt discriminated against by your colleagues. 20. Lost your job. 21. Had your job description or duties changed. 22. Been offered early retirement. 23. Lost your prospect for a promotion. 24. Experienced harassment or discomfort on the job. 25. Had family members exclude you from usual family activities. 26. Had your partner desert you. 27. Lost financial support from family members. 28. Had your child (or children) involuntarily taken away from you. 29. Been advised to not have a child. 30. Been coerced into an abortion or sterilization. 31. Been made to experience discomfort while attending an educational institution. 32. Been dismissed, suspended, prevented from continuing with your education or denied admission into any education institution. 33. Been excluded from any associations/societies/clubs/self-help groups.	(Asia Pacific Network of People Living With HIV/AIDS, 2004) India, Indonesia, Philippines, Thailand

APPENDIX C: SCAN OF QUESTIONS USED TO MEASURE ENACTED STIGMA, GROUPED BY INDICATOR (CONT.)

PEOPLE LIVING WITH HIV/AIDS-LEVEL

INDICATOR	QUESTIONS TO INFORM THE INDICATOR	SOURCE
	Have you ever… 1. Been restricted in your ability to meet with other people living with HIV. 2. Been restricted by your family in your ability to join associations or groups of people living with HIV. 3. Undergone mandatory HIV testing because of pregnancy or illness of your child.	(Asia Pacific Network of People Living With HIV/AIDS, 2004) India, Indonesia, Philippines, Thailand
	Please tell me if these experiences, feelings and opinions are true or false for you: 1. Some people have physically distanced themselves from me (or they would distance themselves from me) upon finding out that I am infected with HIV. 2. Some of the people in my life that I care about have stopped calling me (or they would stop calling me) upon finding out that I have HIV. 3. I have lost (or I would lose friends) if I told them I had HIV. 4. If people found out that I have HIV, they would behave as if they were afraid of me. 5. I have stopped (or I would stop) being close with other people because of the way they would react (or could react) upon finding out that I am infected with HIV. 6. Some people avoid (or would avoid) touching me if they knew that I have HIV. 7. I feel physically ill knowing I have HIV. 8. Having HIV makes me feel dirty. 9. The majority of HIV-positive people are rejected when others find out about it.	(Miric, 2004) Dominican Republic

APPENDIX D:
SCAN OF QUESTIONS USED TO MEASURE DISCLOSURE, GROUPED BY INDICATOR

COMMUNITY-LEVEL

INDICATOR	QUESTIONS TO INFORM THE INDICATOR	SOURCE
Percent of people who think a person should not be able to keep his/her HIV status private.	Would you prefer to know who has HIV/AIDS in your community so that you can be careful not to get infected by him/her?	(B. M. Brown, 2004) South Africa
	How strongly do you agree or disagree with the following statement? (Scale of 1-7) 1. The names of people with AIDS should be made public so others can avoid contact with them.	(Boer & Emons, 2004) Thailand
Percent of people who think a person should be able to keep his/her HIV status private.	Want HIV status kept a family secret (BSS)	(Brown et al., 2004) Ghana, Kenya, Malawi, Uganda, Zambia, Zimbabwe (DHS); Benin, Burkina Faso, Cameroon, Ivory Coast, Niger (BSS)
	If a person learns he/she is infected with the virus that causes AIDS, should the person be allowed to keep this fact private or should this information be available to the community?	
	If kept private, why? 1. Personal problem. 2. People would act differently toward the person if they found out. 3. That person would be isolated/neglected/avoided if others found out. 4. No one would care for that person if others found out. If made available to the community, why? 1. This person is a threat to others/could infect others. 2. This person needs to be isolated. 3. This person needs the care and support of the community. 4. This person gives lesson to others. 5. Other (if other, specify).	(Banteyerga et al., 2004) Ethiopia
Percent of people who fear disclosing their HIV status because of negative reactions.	If you got tested, would you share your test results with anyone? If yes, with whom would you share the test results? 1. Partner 2. Parents 3. Family 4. Neighbors 5. Employer 6. Friends 7. Religious leader 8. Other (if other, specify) If no, why wouldn't you share results with others? 1. Partner would be shattered/angry. 2. Fear of neglect, isolation or avoidance. 3. Fear of verbal abuse, teasing. 4. Fear of being physically abused. 5. Fear of death. 6. I would not receive any care and support. 7. I would be kicked out of the house. 8. People would think that I am bad/immoral. 9. People would think that I am gay. 10. People would think that I am promiscuous. 11. Other (if other, specify).	
	Please answer whether you agree or disagree with the following statements: 1. A person should only tell others that they have AIDS when they are sick and have no choice. 2. It is better not to hide that you have AIDS so you can get support from friends or family.	(Pulerwitz et al., 2004) Brazil

APPENDIX D:
SCAN OF QUESTIONS USED TO MEASURE DISCLOSURE, GROUPED BY INDICATOR (CONT.)

PEOPLE LIVING WITH HIV/AIDS-LEVEL

INDICATOR	QUESTIONS TO INFORM THE INDICATOR	SOURCE
Percentage of people living with HIV/AIDS who have disclosed their status beyond a few trusted individuals (more than five people, including one nonfamily member).	Do you strongly agree, agree, disagree or strongly disagree with each statement: 1. In many areas of your life, no one knows that you have HIV. 2. You work hard to keep your HIV status a secret. 3. You are very careful who you tell that you have HIV. 4. You never feel the need to hide the fact that you have HIV. Have you disclosed your HIV status to anyone within your family? To which family members have you disclosed your HIV status? Have you disclosed your HIV status to anyone within your community? To whom in your community have you disclosed your HIV status?	(FHI, 2004) Nepal
	Have you told anyone about your HIV status? If yes, whom did you tell first? How widely is your HIV status known to others?	(Asia Pacific Network of People Living With HIV/AIDS, 2004) India, Indonesia, Philippines, Thailand
Percent of people living with HIV/AIDS whose HIV status has been disclosed without their consent.	Has a health care worker ever told other people about your HIV status without you wanting them to know? Who has been told about your HIV status without your consent? Have you ever had to disclose your HIV status in order to enter another country?	
Percent of people living with HIV/AIDS who fear and express concern over disclosing their status.	Please tell me if these experiences, feelings and opinions are true or false for you: 1. I am worried thinking that those who know I have HIV will tell that to others. 2. I would like it if my family and my close friends keep my HIV-positive status a secret. 3. I am very careful to whom I tell that I am HIV-positive. 4. To tell someone that I have HIV is something very risky. 5. I make a big effort to make sure that my HIV is kept a secret.	(Miric, 2004) Dominican Republic

APPENDIX E:
SCAN OF QUESTIONS USED TO MEASURE STIGMA THAT CAN BE INTERPRETED AS BELONGING IN MULTIPLE DOMAINS

COMMUNITY-LEVEL

HIV+ student should not attend school (BSS) Person with AIDS should not continue to work (DHS) Should a female teacher with AIDS be allowed to continue teaching in school? (DHS, BSS) Should persons with the AIDS virus who work with other persons such as in a shop, office, or farm be allowed to continue their work, or not? (DHS)	Brown et al., 2004 Ghana, Kenya, Malawi, Uganda, Zambia, Zimbabwe (DHS); Benin, Burkina Faso, Cameroon, Ivory Coast, Niger (BSS)
Please answer whether you agree or disagree with the following statements: 1. I do not want to be friends with someone who has AIDS. 2. People who have AIDS should not be allowed to work.	(Kalichman et al., 2005) South Africa
How strongly do you agree or disagree with the following statements: 1. All AIDS patients should have to live in a special village. 2. I would rather have a heterosexual person as my neighbor than a homosexual person.	(Boer & Emons, 2004) Thailand
If a teacher has HIV/AIDS but is not sick, should she/he be allowed to continue teaching in school?	(Letamo, 2003) Botswana
1. Imagine that you find out that one of your friends is HIV infected. Would you still be friends with him/her? 2. Imagine you meet someone you really like and he/she tells you that he/she is HIV-positive, would you still go out on a "date" with him/her? Please answer whether you agree or disagree with the following statement: People who have AIDS are dirty.	(B. M. Brown, 2004) South Africa
People have many different feelings when they think about people who have AIDS. As I read each of the following feelings, please tell me how you personally feel: 1. Angry at them (person with AIDS)? 2. Afraid of person with AIDS? 3. Disgusted by the person with AIDS? 4. Sorry for the person with AIDS? Please tell me how much you agree or disagree with the following statement: People with AIDS should be legally separated from others to protect the public health. If a teacher has HIV but is not sick, should he or she be allowed to continue teaching in school? If a student has HIV/AIDS, should he or she be allowed to continue attending school?	(Banteyerga et al., 2004) Ethiopia
Please answer whether you agree or disagree with the following statements: 1. A person who has AIDS should not be allowed to make food to sell. 2. If I told my regular partner that I have HIV/AIDS, she/he would leave me. 3. If I had AIDS, I would be fired from my work. 4. People with HIV/AIDS should be required to carry a special identity card. 5. If I saw someone with HIV/AIDS being mistreated, I would try to help him or her. 6. If I learned that a friend of mine had AIDS, I would stop being his/her friend.	(Pulerwitz et al., 2004) Brazil

HEALTH-PROVIDER LEVEL

According to your personal opinion, please tell me if you are or are NOT in agreement with the following: 1. Women with HIV should be prevented from having children. 2. Parental authority should be taken away from people who have HIV.	(Morrison, 2005) Mexico

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ENDNOTES

[1] An attempt to collect all quantitative measures of stigma in Mexico and South Africa, where stigma has been studied extensively, was hindered due to lack of quantitative data (Bollinger, 2005).

[2] Full details of the methodology used to evaluate indicators and questions, as well as for questions asked, but not recommended, are available in the Tanzania study report (Stigma & Discrimination Indicators Working Group, 2005).

[3] Core members of the working group, participating for the past three years: USAID: Cameron Wolf and Billy Pick; MEASURE/Tulane Univ: Lisanne Brown; HORIZONS/Path: Julie Pulerwitz; Policy Project/Futures: Lane Porter; ICRW: Laura Nyblade.

[4] This workshop brought together participants from around the world working on stigma related to HIV/AIDS, leprosy, tuberculosis, disability, mental health, epilepsy and Buruli ulcer.

[5] For example, variations in context may be socioeconomic, cultural or related to experience with type of HIV epidemic (generalized versus localized), length and stage of the epidemic (hidden and spreading versus high rates of visible illness and mortality), and political and social response to it.

[6] The precise items were *"Would you prefer to know who has HIV/AIDS in your community so that you can be careful not to get infected by them?"* in the CSSR study (B. M. Brown, 2004) and "The names of people with AIDS should be made public so others can avoid to have contact with them" (agreement on a scale of 1-7) in the Boer study (Boer & Emons, 2004).

[7] For example, half of the PLHA respondents who were currently in a relationship had not disclosed their status to their partners. Of those who had, the average time from learning status to disclosure to the primary partner was 2.4 years.

[8] We recommend also asking the community-level questions to the health care providers.

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