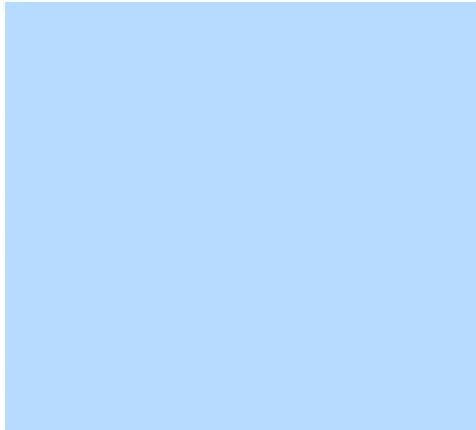
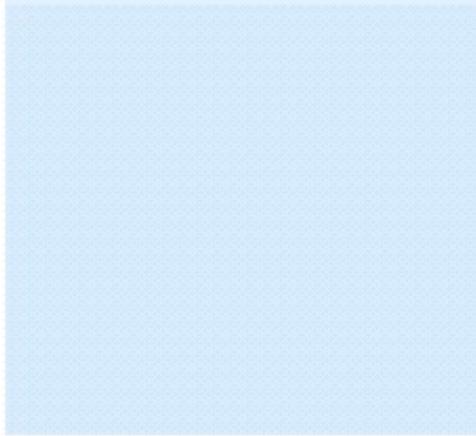


HIV-related Stigma and Discrimination:

A Summary of Recent Literature



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Background

In 2009, over twenty-five years in to the HIV epidemic, HIV-related stigma and discrimination remain highly prevalent across the globe. In the *Declaration of Commitment on HIV/AIDS (2001)* governments throughout the world made commitments to reduce stigma and discrimination against people living with HIV and groups vulnerable to HIV infection. In 2005-2006, country and regional consultations on universal access to HIV prevention, treatment, care and support showed that stigma and discrimination against people living with HIV were major barriers to universal access and undermined the effectiveness of national responses to HIV. In the *Political Declaration of HIV/AIDS (2006)*, in which governments committed to a massive scaling up of programmes to achieve universal access to HIV prevention, treatment, care and support, they also recognized the harmful effects of stigma and discrimination and made major commitments to reduce stigma and discrimination. However, despite the pervasiveness of stigma and discrimination and their harmful impact on HIV responses, the reduction of stigma and discrimination, including through programmes in national AIDS responses, has not been given the attention and resources that are required to make an impact.

To help make these commitments a reality, UNAIDS, in the *Joint Action for Results, UNAIDS Outcome Framework, 2009-2011*, set out nine priority action areas¹. These priorities were selected because their realization will contribute to the achievement of universal access to HIV prevention, treatment, care and support and to the advancement towards related Millennium Development Goals. Reducing stigma and discrimination is essential for achieving successful outcomes within all the priority areas, but among them, one - “*We can remove punitive laws, policies, practices, stigma and discrimination that block effective responses to AIDS*”) - reinforces the need to focus on the reduction of stigma and discrimination.

UNAIDS commissioned, in July 2009, International Center for Research on Women (ICRW) to conduct a review of empirical literature published since 2005 on HIV-related stigma and discrimination. The purpose of the work was to collate recent data and evidence related to the prevalence of HIV-related stigma and discrimination; the relationship between stigma and HIV prevention, treatment, care and support; and results of evaluations of programmes to reduce stigma and discrimination. This paper presents the findings of that review.

Summary of major findings

1. HIV-related stigma—whether measured by stigmatizing attitudes, fear of or perceived stigma, or enacted stigma — is pervasive and negatively impacts the quality of life of people living with HIV.
2. Stigma and discrimination act as impediments to uptake of HIV testing, treatment and care and to adherence to treatment. A consistent, negative association has been found between fear of stigma (or perceived stigma) and use of testing and treatment services. However, it is not yet known if decreased stigma *causes* increased uptake of services, or if increased access to testing and treatment *causes* stigma to fall.
3. There is scant evidence as to a consistent relationship among gender, stigma and use of services. The studies that do exist provide only a fragmentary picture. It suggests that men and women experience stigma differently. According to one study, men may

1) We can prevent sexual transmission of HIV 2) We can prevent mothers from dying and babies from becoming infected with HIV; 3) We can ensure that people living with HIV receive treatment; 4) We can prevent people living with HIV from dying of tuberculosis; 5) We can protect drug users from becoming infected with HIV; 6) We can remove punitive laws, policies, practices, stigma and discrimination that block effective responses to AIDS; 7) We can stop violence against women and girls; 8) We can empower young people to protect themselves from HIV; 9) We can enhance social protection for people affected by HIV

experience more internalized stigma than women while another study indicates that women experience more enacted stigma. Further evidence suggests that women are more easily deterred by stigma from being tested for HIV or seeking care. More studies with an explicit focus on gender are needed to fully understand the full relationship between stigma and use of services among men, women and sexual minorities.

4. In recent years, progress has been made in measuring stigma. However, comparative studies of the prevalence of stigma across settings or populations are rare and made difficult by the diversity of measures used to capture stigma.
5. Stigma and discrimination reduction programmes are too seldom evaluated, and where they are, their evaluation results are too seldom published. Those that have been published indicate that stigma may be decreased through programmatic action using the media, stigma reduction work in communities, through strengthening networks of people living with HIV to take the lead in addressing stigma, and among health care professionals, and possibly through the expansion of treatment services.
6. Evaluated programmes represent a narrow range of all intervention approaches and omit several important and promising programmatic approaches. More evaluations are needed of:
 - Initiatives that seek to empower people living with HIV or to reduce internal stigma and thereby contribute to reducing broader stigma in the community and increasing uptake and adherence of treatment;
 - The costs and cost-effectiveness of stigma-reduction programmes;
 - Programmes implemented at national levels; and
 - Stigma reduction programmes with uptake of testing, treatment, or care and support services as outcome measures.

Introduction

1. HIV-related stigma and discrimination have been acknowledged as an impediment to mitigating the HIV epidemic since its early days, yet programming and activities to reduce stigma and discrimination have been given much less attention than other aspects of the epidemic. Fortunately, in recent years there has been an increase in the literature on HIV stigma as the issue has gained visibility and greater conceptual clarity and as means to measure stigma have been refined (Nyblade and MacQuarrie 2006; Genberg et al. 2008; Stein and Li 2008; Visser et al. 2008). However, key gaps remain in the literature. Definitive studies demonstrating a causal link between the availability of treatment and lower stigma and discrimination, as well as the effect of stigma-reduction interventions on uptake of HIV prevention, care and treatment are lacking. Evaluation data on the potential range of stigma-reduction programmes is still limited, and documentation and evaluation of country programmes are non-existent.

2. This literature review summarizes empirical literature examining the prevalence of HIV stigma and discrimination and the relationship between stigma and HIV prevention, treatment and care, as well as evaluations of programs to reduce HIV-related stigma and discrimination. Publications in this literature review were published between mid-2005 and July 2009. Structured searches of peer-reviewed journal articles were conducted using Social Science Citation Index, Sociological Abstracts, JSTOR, MEDLINE, EBSCO and Popline in July 2009. Searches for documentation on anti-stigma interventions extended to institutional reports and other publications not subject to peer review located through Popline and a search of World Bank's Development Gateway, USAID's DEC, and numerous organizational websites. Search terms included "HIV/AIDS stigma" "discrimination," "prevalence", "treatment", "ARV" "ART", "care and support" "care-giving", "VCT" "PMTCT", "testing", "adherence", "services", "access", "utilization", "uptake", "program", "intervention", "policy", "evaluation", and related terms. The literature search resulted in 206 articles that met the criteria of inclusion.

Prevalence of HIV stigma and discrimination

3. A plethora of quantitative studies confirm that HIV-related stigma and discrimination are highly prevalent and feature prominently in the lives of people living with HIV in settings with epidemics as diverse as the United States, Vietnam, and South Africa. Comparison of prevalence across region or sample is complicated by the differences among stigmatizing incidents inquired about as well as different time-frames. The experience of stigma² was universal among a small sample in Brazil, and nearly universal among a sample of women in Vietnam (Melchior et al. 2007; Brickley et al. 2008). One study in the US indicated that 8 out of 10 families experienced discrimination (Bogart et al. 2008). In contrast, another study of women with HIV in the US found the prevalence of enacted stigma to be lower, at around 17% of the sample (Wingood et al. 2007). A large household-based study in Kenya found that 75% of HIV-positive respondents had experienced "enacted stigma" (Odindo and Mwanthi 2008). Slightly more than one-half of respondents experienced "enacted stigma" in a China sample (Li et al. 2009) as had one-third of respondents in South India (Subramanian et al. 2009). In the Dominican Republic, a study highlighted the importance of "verbal stigma", with more than 60% reporting being gossiped about and between 25-30% reporting verbal abuse. Furthermore, the study found striking gender differences, with women

² The multiple terms here reflect the variation in terms employed by different studies on stigma and discrimination and are repeated in this article according to the respective authors' original use of these terms. "Experience of stigma", "discrimination", and "enacted stigma" all refer to a common underlying phenomenon, that is, differential treatment based on real or perceived HIV status. However, use of the term "experience of stigma" or "enacted stigma" may occasionally reflect a wider set of items being measured than is sometimes connoted by the term "discrimination".

experiencing more of nearly every form of “enacted stigma”—a pattern found in earlier work in Tanzania—and gender-based violence emerging as a prominent concern as well (MacQuarrie, Nyblade, Philip, Kwesigabo and Mbwambo 2006; Urena 2009).

4. In India, “perceived stigma”³ or fear of stigma were common—nearly universal in one study—even where reports of “enacted stigma” were low (Priya and Sathyamala 2007; Steward et al. 2008; Subramanian, Gupte, Dorairaj, Periannan and Mathai 2009), a pattern also found in the U.S. (Bogart, Cowgill, Kennedy, Ryan, Murphy, Elijah and Schuster 2008). Where such data was elicited, respondents reported experiencing (or fearing) stigma by general community members or friends and acquaintances, followed by health providers (Cao et al. 2006; Yu et al. 2009; Zukoski and Thorburn 2009).

5. While most studies did not distinguish “enacted stigma” according to its source, several studies explored stigma and discrimination in particular institutional settings. Two separate studies in the US, one of housing project clients and the other of ART clients, found that approximately 40% of their respondents had experienced discrimination in the health care system (Sohler et al. 2007; Thrasher et al. 2008). A multi-country qualitative study in Lesotho, Malawi, South Africa, Swaziland, and Tanzania documented “extensive” verbal and physical abuse and neglect in health services, reported by both participants and nurses (Dlamini et al. 2007). An Australian study highlights an important gender component: women reported significantly higher rates of discrimination in health services, though there was a decline in reports of incidents for both men and women (Thorpe et al. 2008). Studies of attitudes among health workers also found stigmatizing views to be high (Mahendra et al. 2006; Sadoh et al. 2006; Li et al. 2007; Li et al. 2007; Mahendra et al. 2007; Webber 2007; Oanh, Ashburn, Pulerwitz, Ogden and Nyblade 2008; Stein and Li 2008; Chirwa et al. 2009). A prospective study in France examined employment discrimination specifically and found that 149 out of 478 people living with HIV experienced employment loss over the duration of the study (Dray-Spira et al. 2008). Studies among employers in both China and Nigeria found strong reluctance to hire or retain employees with HIV (Adeyemo and Oyinloye 2007; Rao et al. 2008), suggesting that the workplace is a setting for potential discrimination regardless of region.

6. Numerous household surveys and other probability-sampled surveys reported extensive stigmatizing attitudes among the general population across all samples studied in settings as diverse as China, US, Hong Kong, South Africa, Jamaica, Brazil, Nigeria, Thailand, Tanzania, Zimbabwe, Burkina Faso, Zambia, and Ghana (Chen et al. 2005; Emler 2005; Lau and Tsui 2005; Hongjie et al. 2006; Mak et al. 2006; Maughan-Brown 2006; Norman et al. 2006; Visser et al. 2006; Chan et al. 2007; Chen et al. 2007; Lau and Tsui 2007; Ndinda et al. 2007; Bunn et al. 2008; Chiu et al. 2008; Garcia et al. 2008; Stein and Li 2008; Babalola et al. 2009; Genberg et al. 2009; Norman et al. 2009; Stephenson 2009; Visser et al. 2009). Furthermore, stigmatizing attitudes do not apply to all people living with HIV equally. One study of attitudes among women in Puerto Rico, for instance, found that there was significantly less sympathy for people living with HIV who were drug users, somewhat more for people living with HIV described as homosexual, and the most sympathy for children and heterosexual women with HIV (Norman, Abreu, Candelaria and Sala 2009).

³ “Perceived stigma” is differentiated from “enacted stigma” in that it reflects respondents’ beliefs or perceptions about the magnitude of stigma in a geographically defined area. “Enacted stigma” refers to stigma experienced and reported by a person living with HIV, and is sometimes expressed in count data before being aggregated in an index or scale. Occasionally, “observed enacted stigma”, that is, incidents of stigma witnessed directly by someone other than the individual experiencing it, are reported. “Observed enacted stigma” has been measured in facility-based studies in which health providers report on stigma in their work environments (Oanh et al. 2008) and in general community surveys (Nyblade et al. 2008; Sambisa 2008).

7. Direct comparison of stigmatizing attitudes across countries was not possible, however, where studies were not measuring the same aspect of stigma or are not doing so in an equivalent manner. For example, one multi-site study found that HIV stigma was highest in Tanzania, followed by Thailand and Zimbabwe, and lowest in two South African sites when measured by a Negative Attitudes Scale; but highest in Zimbabwe followed by Tanzania and Soweto, South Africa and lowest in Thailand and Vulindlela, South Africa when stigma was measured by Perceived Discrimination and that these two scales correlated poorly (Genberg, Hlavka, Konda, Maman, Chariyalertsak, Chingono, Mbwambo, Modiba, Van Rooyen and Celentano 2009).

HIV Stigma as a Barrier to HIV Prevention, Treatment, Care and Support

8. A substantial body of literature, both qualitative and quantitative, has emerged to convincingly support the hypothesis that stigma inhibits access to services and adherence to treatment.

Testing

9. The vast majority of data on the relationship between stigma and HIV testing comes from sub-Saharan Africa. While willingness to test for HIV was high (89%) among antenatal clients in Nigeria, women who were unwilling to be tested cited strong fears of stigma should they test positive for HIV (Adeneye et al. 2006). In contrast, only 33% of a sample of antenatal clients had been tested for HIV in Botswana. Women who declined to test did not believe stigma to be a substantial reason for refusing an HIV test, but concerns about the confidentiality of results were a substantial reason for refusing a test (Creek et al 2009). Fear of stigma and discrimination were dominant reasons for the 60% of pregnant women who refused HIV tests in a Vietnam study (Thu Anh et al. 2008).

10. Similarly, stigma was cited as a primary barrier to using VCT services in Botswana, South Africa, Tanzania, Thailand, Uganda, and Zimbabwe (Wolfe et al. 2006; Bwambale et al. 2008; Khumalo-Sakutukwa et al. 2008). "Perceived stigma" was a predictor for declining to test for HIV among both men and women in a study of Nigerian youth and adults in South Africa (Hutchinson and Mahlalela 2006; Babalola 2007a). In South Africa, the effect of perceived stigma on avoiding VCT was stronger for women than it was for men (Hutchinson and Mahlalela 2006). Respondents' own stigmatizing attitudes were negatively associated with likelihood of having tested for HIV in another Cape Town, South Africa study and in Brazil, one of the few studies on VCT and stigma outside of Sub-Saharan Africa (Kalichman and Simbaya 2007; Pulerwitz et al. 2008). In contrast to the majority of literature on the relationship between stigma and testing, a study in Zimbabwe found that uptake of testing was significantly higher among those women and men who had observed enacted stigma, though the study could not determine whether observed enacted stigma occurred before or after testing (Sambisa 2008).

Uptake and Adherence to Anti-retroviral Therapy

11. The role of stigma in *reducing uptake* of ART is unclear. Stigma emerged spontaneously as the second most frequently listed reason women do not begin ART in a qualitative study in Zambia; but in a Nigeria study of men and women, less than 4% of respondents feared stigma (Murphy et al. 2006; Ogunro et al. 2006). One explanation for such apparently contradictory findings may lie with the gender of the respondents as a third study notes that the use of ART services is influenced by stigma, and by the social and economic costs of accessing services, all of which are experienced differently by men and women (Nyirenda et al. 2006). A study of directors of NGOs providing HIV-related services reported that a majority believed HIV-positive women were especially vulnerable to negative social consequences, which impedes access to a range of services (Benotsch et al. 2008).

12. The evidence is much clearer that stigma and discrimination present barriers to *good adherence* to ART. Perceived stigma and internal stigma were inversely associated with adherence in the US, United Kingdom, Brazil, Botswana, and China (Roberts 2005; Stirratt et al. 2006; Ware et al. 2006; Calin et al. 2007; Melchior, Nemes, Alencar and Buchalla 2007; Rajabiun et al. 2007; Rao et al. 2007; Nam et al. 2008; Sabina et al. 2008; Thrasher, Earp, Golin and Zimmer 2008; Dlamini et al. 2009; Kip et al. 2009; Naidoo et al. 2009). In analyses using multi-variate models, this relationship persisted when controlling for other factors. In one US study, patients with high stigma concerns were 3.3 times more likely to not adhere to their ART regimen (Dlamini et al 2009). However, a study in Peru demonstrated that stigma decreased and adherence improved with intensive investments in daily adherence support (Franke et al 2008).

13. A related finding from qualitative studies on the context of prevention of mother-to-child transmission services in Malawi and South Africa is that fear of stigma and discrimination, along with fear of household conflict, divorce, and lack of support from husbands, was oft-cited as a reason for women dropping out following their initial antenatal clinic visit (Bwirire et al. 2008; Varga and Brookes 2008). Women also expressed concern about the focus on the health of the infant and worried about access to ART for themselves.

Other Health Services

14. Studies in New Mexico, Alabama and Mississippi, US found strong gender differences in the use of health services. While the experience of stigma was implicated in avoiding care-seeking for all, women reported more stigma and avoided seeking health care more often than men, resulting in poorer health outcomes (Wingood, Diclemente, Mikhail, McCree, Davies, Hardin, Peterson, Hook and Saag 2007; Dunn et al. 2009).

15. Delayed treatment-seeking among Zimbabwean men was also attributed to fear of stigma, particularly for sexual health concerns (Pearson et al 2008), and respondents with a history of TB in the family reported in in-depth interviews that renewed stigma of TB as a marker of HIV discouraged individuals to access or complete treatment of TB in South Africa (Moller and Erstad 2007).

16. Fears of stigma are supported by dismaying reports of discrimination within health care settings. HIV discrimination in health settings was reported by one in six respondents in Alabama and Mississippi, US, and 40% of ART clients in a second US study of 28 urban areas and 24 rural counties (Wingood, Diclemente, Mikhail, McCree, Davies, Hardin, Peterson, Hook and Saag 2007; Thrasher, Earp, Golin and Zimmer 2008). Studies in several Indian locations reported health services to be the predominant setting in which discrimination occurs; in one study a quarter of people living with HIV had been refused medical care (Mulye et al. 2005; Marfatia et al. 2007).

Home-based Care and Support

17. Evidence from Kenya suggests that quality of care by family members is improved when stigma is low. Less expressed stigmatizing attitudes were associated with greater care and support knowledge and insights into the needs of children under their care (Hamra et al 2005). While provision of care activities within the home is sometimes an explicit attempt to avoid potential discrimination at formal services, families caring for an HIV-positive family member cite fear of stigma from community members as a dominant concern. Home-based care professionals also report stigma to feature strongly as a barrier to introducing home-based care services (Waterman et al. 2007).

Does Expanded Access to ART Reduce Stigma?

18. The idea that expansion of ART can reduce stigma and discrimination is a powerful one, but the evidence is, as yet, tentative. This is in part because there are few places that have

achieved near-universal access to ART for a sufficiently long period of time to exert influence on stigma and in part because the lack of quasi-experimental study designs⁴ make it difficult to attribute changes in stigma to changes in ART availability. However, the limited analyses available suggest that expanded ART services have beneficial effects on stigma. Ethnographic work in Sao Paulo, Brazil indicates that children's experience with stigma shifted over their life trajectories and that HAART was a substantial factor in reducing stigma (Abadia-Barrero and Castro 2006). A pre/post survey of community attitudes that lacked a comparison group in South Africa demonstrated a reduction in HIV stigma one year after ART became available (Forsyth et al. 2008), and a cross sectional study in Botswana found significantly lower odds of stigmatizing attitudes in communities with ART available in or near their village, though the lack of longitudinal data makes the causal direction difficult to ascertain (Wolfe et al. 2008). These are promising results that will hopefully be confirmed in the coming years with increased pursuit of universal access and more rigorous evaluation research that can establish more than an association, but a causal link.

Stigma-reduction Interventions

19. Documented evaluations of programmes to reduce HIV stigma and discrimination lag behind research on the prevalence of stigma or its relationship to uptake of services. Furthermore, the evaluation data available is unlikely to be fully representative of the range of anti-stigma interventions being implemented. For example, a search for programmes on Popline yielded more than 200 results since 2005, but only a half dozen of those met inclusion criteria of having stigma reduction as a primary or secondary objective and having conducted an evaluation with an outcome measure of stigma. An essential component to the effective response to HIV stigma are programmes working with and led by people living with HIV, such as the promising approach taken by the multi-country People Living with HIV Stigma Index initiative (Urena 2009). Yet there were no published evaluations of these programmes' impacts on stigma to date, a glaring gap in the literature.

20. Programme activities using the media and mass communications appear especially likely to have evaluations. One Ghanaian programme that used religious leaders to convey compassionate messages showed that stigmatizing attitudes declined, sometimes dramatically, both over time and with exposure to the campaign (Boulay et al. 2008). Exposure to edutainment programs, such as serial dramas aired on TV or radio, was correlated with more accepting attitudes in Botswana and Kyrgyzstan, but no significant relationship was found with a similar programme in Malawi (O'Leary et al. 2007; Pappas-DeLuca et al. 2008; Rimal and Creel 2008; Adams 2009). Another study in Nigeria that used a household survey found that personal exposure to HIV messages in the media was significantly and positively associated with accepting attitudes, but this effect worked predominantly through exposure's effect on increasing HIV-related knowledge (Babalola, Fatusi and Anyanti 2009).

21. Several community-based interventions with multiple activities demonstrated significant changes in stigma at the community level in Thailand, Tanzania, Vietnam and Zambia (Apinundecha et al. 2007; Nyblade et al. 2008; Nyblade, MacQuarrie, Kwesigabo, Jain, Kajula, Philip, Henerico Tibesigwa and Mbwambo 2008; Samuels et al. 2008). Each of these programmes focused on community participation and interaction. While all of these programmes included awareness-raising and sensitization and HIV knowledge awareness, the exact content and modalities of these programmes are too diverse to easily glean which approaches are most responsible for their success. Interventions studies in Vietnam and Tanzania suggest that opportunities for sustained dialogue about values and beliefs is

⁴ Quasi-experimental studies typically combine a pre/post and treatment (or intervention) and comparison arm design and attempt to account for possible confounding variables, but, unlike experimental designs, lack randomization at the individual level.

important for reducing more than fear-based stigma and tackling other drivers of stigma. Some community programmes included the provision of services, including home-based care, VCT, or ART (Attawell et al. 2005; Khumalo-Sakutukwa, Morin, Fritz, Charlebois, van Rooyen, Chingono, Modiba, Mrumbi, Visrutaratna, Singh, Sweat, Celentano and Coates 2008; Samuels, Simbaya, Sarna, Geibel, Ndubani and Kamwanga 2008). Their impact on community and internal stigma may be due to the increased access to services or to their anti-stigma messages and counselling, or to a synergistic effect among these components.

22. Interventions to reduce stigma among providers in health care settings in India, Ghana, Tanzania, Vietnam, and China also showed improvements in stigmatizing attitudes and discriminatory care practices over time or in comparison to control groups (Mahendra, Gilborn, George, Samson, Mudoi, Jadav, Gupta, Bharat and Daly 2006; EngenderHealth 2007; Oanh, Ashburn, Pulerwitz, Ogden and Nyblade 2008; Wu et al. 2008). Additional effective interventions included a micro-credit programme in Thailand that partners HIV-positive and negative loan recipients, a school-based programme and a workplace intervention in South Africa (Bell et al 2008)(Esu-Williams et al. 2005; UNAIDS 2007; Viravaidya et al. 2008).

Remaining Gaps

23. In summary, the literature reviewed here indicates that stigmatizing attitudes related to HIV are pervasive, and fear of stigma and enacted stigma are commonplace; that stigma and discrimination are major impediments to HIV testing, treatment and care; and that stigma may be decreased through programmatic action using the media, in communities, through strengthening networks of people living with HIV to take the lead in addressing stigma, and among health care professionals or possibly through the expansion of treatment services. The increased body of literature on the topic since 2005 has increased our understanding of HIV stigma, but several notable gaps remain.

24. First, great strides have been made in understanding how to measure stigma. Yet there continues to be a wide diversity of measures used, making it difficult to compare prevalence of stigma across settings or populations. More comparative studies would help policymakers and programme implementers identify those locations where stigma is likely to pose the greatest barriers to uptake and adherence to HIV testing, treatment, and care services.

25. Secondly, there is scant evidence as to the relationship between gender, stigma and access to services; and that which exists does not present a wholly consistent picture. Studies in South Africa have found that men internalize stigma to a greater extent than women; while evidence from Tanzania finds women experience more enacted stigma than men (MacQuarrie, Nyblade, Philip, Kwesigabo and Mbwambo 2006; Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo 2007). Studies in the US have found that women with HIV are less likely to seek health care than are their male counterparts; and in another study in South Africa, women are more likely to avoid testing than men at the same levels of perceived stigma (Hutchinson and Mahlalela 2006; Wingood, Diclemente, Mikhail, McCree, Davies, Hardin, Peterson, Hook and Saag 2007; Dunn, Green Hammond and Roberts 2009). Are men or are women more consistently deterred by stigma from using services? To what extent do these studies portray a universal pattern and to what extent do they reflect parts of uniquely regional patterns?

26. Third, definitive evidence of the “stigma-reducing effects” of universal or greater access to treatment services is lacking. As access to treatment expands, rigorous, quasi-experimental evaluations should be encouraged in order to further contribute to our understanding of the relationship between stigma and treatment. Additionally, definitive evidence testing the relationship between stigma reduction interventions and uptake of HIV prevention, care and treatment services is needed. Similarly, it is not known whether

increased use of HIV testing services is associated with less stigma and discrimination, and if so, whether increased testing works to reduce stigma and discrimination through a greater proportion of the population knowing their HIV status or through the content of counselling sessions that may accompany testing.

27. On the programme side, an insufficient number of stigma reduction programmes are accompanied by published evaluations. Those that are published represent a narrow range of intervention approaches, omitting completely those that seek to empower people living with HIV or to reduce internal stigma as approaches to reducing broader stigma in the community and increasing uptake and adherence of treatment. Other notable omissions include data on the costs and cost-effectiveness of stigma-reduction programmes, evaluations of national-level programmes, and evaluations that describe whether uptake of testing, treatment, care and support services increases in response to reduced stigma. Furthermore, available evaluation data disproportionately describe intervention successes. Programme implementers have as much to learn from approaches or aspects of programmes that *do not* impact stigma as from those that do impact stigma. Finally, despite the widespread global agreement of the importance of addressing stigma and discrimination to support an effective HIV response, strategic, coordinated and comprehensive programmes for stigma and discrimination reduction at the country level are missing.

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