

July 2012

## STIGMA AND DISCRIMINATION: KEY BARRIERS TO ACHIEVING GLOBAL GOALS FOR MATERNAL HEALTH AND ELIMINATION OF NEW CHILD HIV INFECTIONS

*Working  
Paper  
No. 4*

This publication was prepared by Janet Turan, Laura Nyblade,  
and Philippe Monfiston of the Health Policy Project.

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Suggested citation: Turan, J., L. Nyblade, and P. Monfiston. 2012. "Stigma and Discrimination: Key Barriers to Achieving Global Goals for Maternal Health and the Elimination of New Child HIV Infections." *Working Paper #4*. Washington, DC: Futures Group, Health Policy Project.

The Health Policy Project is a five-year cooperative agreement funded by the U.S. Agency for International Development under Agreement No. AID-OAA-A-10-00067, beginning September 30, 2010. HIV-related activities under the project are supported by the President's Emergency Plan for AIDS Relief (PEPFAR). The project is implemented by Futures Group, in collaboration with the Centre for Development and Population Activities (CEDPA), Futures Institute, Partners in Population and Development, Africa Regional Office (PPD ARO), Population Reference Bureau (PRB), RTI International, and the White Ribbon Alliance for Safe Motherhood (WRA).

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# Stigma and Discrimination: Key Barriers to Achieving Global Goals for Maternal Health and the Elimination of New Child HIV Infections

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**JULY 2012**

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# CONTENTS

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Acknowledgments .....	iv
Executive Summary .....	v
Abbreviations .....	vii
I. Introduction .....	1
II. Background .....	2
III. Methodology .....	6
IV. Results .....	7
Stigma, Discrimination, and the PMTCT Cascade .....	7
How Stigma and Discrimination Impact Each Step in the PMTCT Cascade .....	10
<i>Initiating use of ANC</i> .....	10
<i>Being offered an HIV test</i> .....	10
<i>Accepting HIV testing</i> .....	10
<i>Enrolling in PMTCT or HIV treatment services</i> .....	11
<i>Adhering to ART and follow-up visits during pregnancy</i> .....	11
<i>Giving birth with a medically trained attendant</i> .....	12
<i>Adhering to recommended infant feeding practices</i> .....	12
<i>Adhering to maternal and infant follow-up visits and antiretrovirals (ARVs) after the birth</i> .....	12
<i>Bringing infant for HIV testing</i> .....	12
The Cumulative Effects of Stigma and Discrimination Across the PMTCT Cascade .....	13
Integration of ANC/MNCH/FP and HIV Services: Will it Remove Stigma and Discrimination (S&D) as a Barrier to PMTCT and Cause of Loss to Follow-Up? .....	13
V. Recommendations .....	17
Global and National Policy Level .....	17
Health Facility Level .....	18
Client and Community Level .....	19
VI. Conclusions .....	21
Annex A. 2010 Revised WHO PMTCT guidelines .....	22
Annex B. Effects of HIV-related Stigma and Discrimination at Each Step of the Cascade .....	23
References .....	27

## ACKNOWLEDGMENTS

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The authors are grateful for the thoughtful comments of Ronald MacInnis and Beth Robinson of the Health Policy Project; Jayne L. Kulzer and Arbogast Oyanga of Family AIDS Care and Education Services (FACES, Kenya); and Benjamin Ryan Phelps, Michelle Wu Yoon, and Jose Gutierrez of the United States Agency for International Development. The authors also thank Ginny Gordon, Lori Merritt, and Tasnim Shahjahan for their editorial and graphic support.

## EXECUTIVE SUMMARY

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The global community has set two important goals: the virtual elimination of vertical transmission of HIV and a 50 percent reduction in HIV-related maternal mortality by 2015. Although much progress has been made in expanding prevention of mother-to-child transmission (PMTCT) services, recent data reveal enduring, serious challenges, such as the low uptake and use of proven effective interventions for PMTCT in many settings. While the need to expand the supply of services continues, mounting evidence demonstrates an urgent need to examine and respond to demand-side barriers that affect women's initiation and retention in PMTCT programs. Key among these barriers are stigma and discrimination.

The Health Policy Project team reviewed the existing academic and programmatic literature to examine the current evidence on stigma and discrimination and their negative impacts on PMTCT and family health. As part of this review, the team examined how stigma and discrimination act as barriers at each step in the complex series of interventions that women and infants must complete for successful PMTCT (characterized as “the PMTCT cascade”). The team also explored how and whether the integration of PMTCT, antenatal care (ANC), and maternal, neonatal, and child health (MNCH) services may mitigate the negative effects of stigma and discrimination. The data were then used to develop recommendations for programmatic actions to integrate strategies aimed at the reduction of stigma and discrimination into PMTCT and ANC and MNCH services.

The literature review revealed a wealth of both quantitative and qualitative data from low-resource settings worldwide, indicating that HIV-related stigma and discrimination can negatively impact service uptake and adherence for women and infants at each step of the PMTCT cascade. The negative effects of fears and experiences of HIV-related stigma and discrimination begin with initial use of ANC services during pregnancy and continue to affect PMTCT and maternity service use throughout pregnancy, birth, and the postnatal period. The multiple steps required to successfully complete a full program of PMTCT all increase the potential for inadvertent, unwanted disclosure of HIV status, heightening both women's fears of and the possibility of experiencing stigma and discrimination at each step along the cascade.

Modeling exercises indicate that these effects of stigma and discrimination are cumulative across the PMTCT cascade and therefore may significantly affect HIV infection rates among infants. One model estimated that 44 percent of all vertical HIV transmissions could be averted if stigma and discrimination could be markedly reduced (Prudden, Dzialowy et al. Forthcoming). Another estimated that a highly effective stigma reduction program could reduce infant infections by as much as 33 percent (Watts, Zimmerman et al. 2010). Although the trend toward PMTCT and ANC and MNCH service integration in health facilities has the potential to reduce women's experiences of stigma and discrimination, there are indications that service integration on its own will not be enough to eliminate the negative effects of stigma and discrimination on PMTCT service use.

Alongside important modifications to make clinical services more effective, convenient, and accessible for pregnant women in low-resource settings, there is also a need to integrate HIV-related stigma reduction components into PMTCT, ANC, and MNCH services. Fortunately, there are existing stigma and discrimination reduction tools and intervention models, as well as measures to evaluate progress, that can be easily integrated into these services.

This paper presents strategies that can be used to

1. Identify, address, and monitor stigma in ANC, MNCH, PMTCT, and labor and delivery service settings (including meeting the needs of service providers);
2. Develop programs that directly address the expressed needs of women of reproductive age;

3. Involve women living with HIV in service delivery;
4. Positively engage the communities and male partners of pregnant women living with HIV;
5. Design PMTCT media campaigns with the participation and input of advocacy groups and pregnant women living with HIV; and
6. Advocate for the development and implementation of national and regional policies that protect the rights of persons living with HIV and that mandate humane and non-discriminatory treatment.

It is unlikely that the global commitment to virtual elimination of vertical transmission and reduced HIV-related maternal mortality by 2015 will be met unless major efforts at the global, national, community, and facility levels are made to identify and counter the multiple manifestations of HIV-related stigma and discrimination facing pregnant women. While it has yet to be fully recognized, reducing stigma and discrimination is an essential piece of delivering care for all women, men, and children. Women of reproductive age—and especially pregnant women—are particularly vulnerable to the adverse effects of HIV-related stigma and discrimination. Furthermore, high levels of HIV-related stigma in the community and in health facilities may negatively affect all women, not just those who know they are HIV positive.

In response, global, national, district, and local health strategies and operational plans should include interventions to reduce and mitigate HIV-related stigma and discrimination in PMTCT, HIV, and MNCH services. These strategies and plans need to set targets for stigma reduction, measure the impact of stigma reduction interventions on service uptake, allocate resources (staff and financing) for interventions, and monitor the interventions and policies aimed at reducing HIV-related stigma and discrimination.

## ABBREVIATIONS

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AIDS	acquired immune deficiency syndrome
ANC	antenatal care
ART	antiretroviral therapy
ARV	antiretroviral
CI	confidence interval
FACES	Family AIDS Care and Education Services
FP	family planning
HAART	highly active antiretroviral therapy
HIV	human immunodeficiency virus
L&D	labor and delivery
MAMAS	Maternity in Migori and AIDS Stigma
MNCH	maternal, neonatal, and child health
OR	odds ratio
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
S&D	stigma and discrimination
TB	tuberculosis
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization



# I. INTRODUCTION

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The United Nations Program on HIV/AIDS (UNAIDS) estimates that, in 2009, 370,000 children globally became newly infected with HIV and an estimated 42,000–60,000 pregnant women died of AIDS-related causes (UNAIDS 2011). This situation persists despite strong evidence pointing to the effectiveness of antiretroviral therapy (ART) for improving maternal health and preventing mother-to-child transmission; vertical transmission rates as low as 1–2 percent can now be achieved in both high- and low-resource settings worldwide (Lehman, John-Stewart et al. 2009; Mofenson 2010). With this promise, the global community has set two important goals: virtual elimination of vertical transmission of HIV and a 50 percent reduction in HIV and AIDS-related maternal mortality by 2015 (UNAIDS 2011).

Much progress has been made globally in expanding prevention of mother-to-child transmission (PMTCT) services (WHO, UNAIDS et al. 2011). However, recent data indicate that serious challenges remain, such as the low uptake and use of proven effective interventions for PMTCT in many settings (Sripipatana, Spensley et al. 2007; Stringer, Ekouevi et al. 2010). While the need to expand the supply of services continues, mounting evidence demonstrates an urgent need to examine and respond to demand-side barriers that affect women’s initiation and retention in PMTCT programs. Key among these barriers are stigma and discrimination.

In the context of (1) pervasive stigma and discrimination in many women’s lives, (2) the growing integration of HIV testing and treatment into antenatal care (ANC) and maternal, neonatal, and child health (MNCH) services, and (3) the multiple steps HIV-positive women must navigate to receive the “cascade” of interventions necessary to prevent mother-to-child transmission (known as the “PMTCT cascade”), the Health Policy Project team reviewed existing literature to examine current evidence on stigma and discrimination and their negative impacts on PMTCT and family health. The team examined how stigma and discrimination act as barriers at each step of the PMTCT cascade and explored how and whether the integration of PMTCT and ANC and MNCH services may mitigate the negative effects of stigma and discrimination. The data were then used to develop recommendations for programmatic actions to integrate the reduction of stigma and discrimination into PMTCT and ANC and MNCH services.

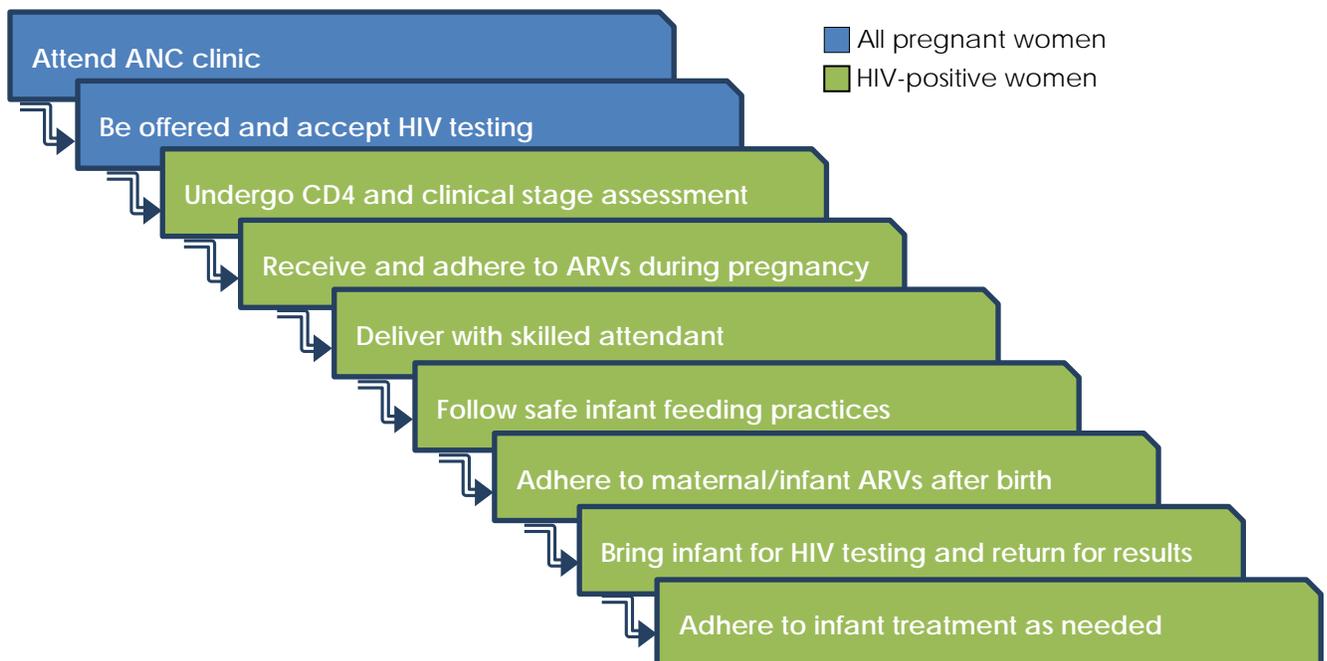
## II. BACKGROUND

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In the past decade, the global community has addressed the urgent issue of maternal and infant HIV infection by focusing on what are now known as the four pillars of PMTCT: (1) prevention of HIV in women; (2) prevention of unintended pregnancies among women living with HIV; (3) prevention of transmission from a woman living with HIV to her infant; and (4) care and support for women living with HIV, their infants, and their families (Coutsoudis, Kwaan et al. 2010). In many countries, great strides have been made in establishing the services needed for effective PMTCT (mainly focusing on the third pillar)—such as making appropriate ART drug regimens available for pregnant women and infants, updating and disseminating infant feeding recommendations, scaling up PMTCT services in primary healthcare facilities, integrating PMTCT into ANC and MNCH services, and making efforts to ensure that PMTCT programs also address the health needs of the woman and the whole family (the fourth pillar) instead of exclusively focusing on preventing transmission to the infant (Betancourt, Abrams et al. 2010). Although the supply-side issues are by no means solved in many locations globally, there has been a great expansion of PMTCT services, especially in high-priority countries with high HIV prevalence (World Health Organization, UNAIDS et al. 2009).

Successful PMTCT requires women and infants to receive a cascade of interventions (Padian et al., 2011)—ranging from the uptake of ANC services and HIV testing during pregnancy, to the use of ART by pregnant women living with HIV, to safe childbirth practices and appropriate infant feeding, and to the uptake of infant HIV testing and other postnatal health services (see Figure 1).

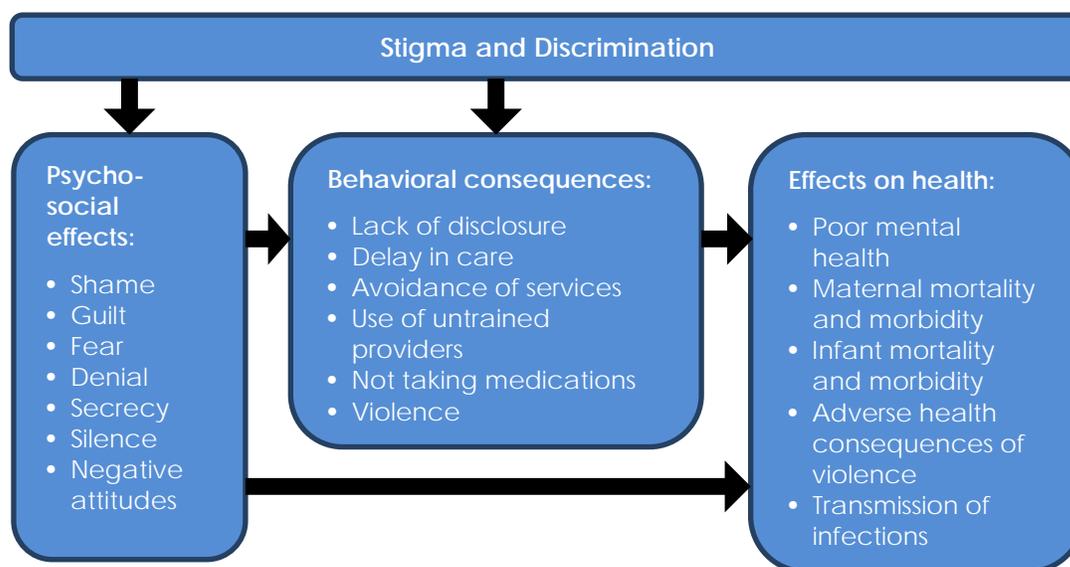
Figure 1: The PMTCT Cascade



One key social factor that limits successful completion of the PMTCT cascade—and thereby women’s, men’s, and children’s health and well-being—is the persistence of stigma and discrimination surrounding HIV and AIDS. The multiple steps required to successfully complete a full program of PMTCT—and as the science advances, to adhere to the increasingly more complex antiretroviral regimens for PMTCT (see Annex A)—all increase the potential for inadvertent, unwanted disclosure of HIV status, heightening both fears of stigma and discrimination, as well as the possibility of experiencing stigma and discrimination at each step along the cascade.

For all people living with HIV (PLHIV), theoretical frameworks and a wealth of research on HIV-related stigma and discrimination have shown that different dimensions of stigma—anticipated stigma, perceived community stigma, enacted stigma (discrimination), and self-stigma—adversely affect quality of life, healthcare access, and health outcomes (Steward, Herek et al. 2008; Earnshaw and Chaudoir 2009; Holzemer, Human et al. 2009). Further, some research suggests that stigma from close persons may have a bigger impact (Brickley, Le Dung Hanh et al. 2009; Brown, Belue et al. 2010; Turan, Bukusi et al. 2011). Figure 2 illustrates how HIV-related fears and experiences of stigma can lead to a series of known, negative psycho-social effects, which in turn lead to behavioral consequences (such as lack of disclosure and avoidance of health services), which can result in negative maternal, infant, and paternal health outcomes.

**Figure 2: A Framework for the Effects of Stigma on Maternal, Neonatal, and Child Health**

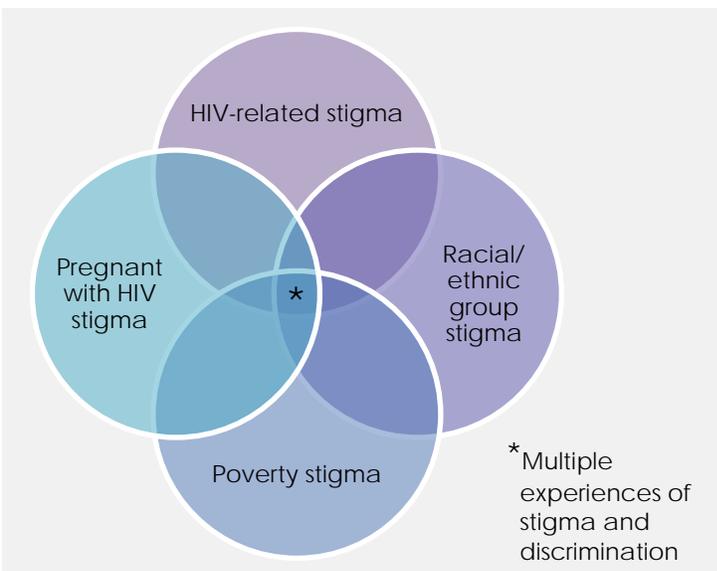


Adapted from Kumar et al., *Culture, Health, and Sexuality*, 2009.

Women of reproductive age—and especially pregnant women—are particularly vulnerable to the adverse effects of HIV-related stigma and discrimination. Because a pregnant woman is often the first family member to be tested for HIV, she is vulnerable to blame for bringing the virus into the family and often suffers from adverse consequences of her HIV-positive status disclosure (Bond, Chase et al. 2002; Turan, Miller et al. 2008). These factors are compounded in many settings by gender norms or relations that penalize women for perceived promiscuity (often assumed of persons living with HIV) and place women in positions of socio-economic vulnerability (Sandelowski, Lambe et al. 2004; Strebel, Crawford et al. 2006).

Furthermore, women of reproductive age living with HIV often struggle with the challenges of multiple stigmas (Bunting 1996; Chase and Aggleton 2001; Sandelowski, Lambe et al. 2004; Esplen 2007; Brickley, Le Dung Hanh et al. 2009). In addition to the stigma of being HIV-positive, these can include the stigma associated with having a child while HIV positive (Barnes and Murphy 2009), or conversely, of being childless or using family planning (FP) in societies that strongly value fertility (Kisakye, Akena et al. 2010; Upton and Dolan 2011); stigma of being poor or uneducated (Mickelson and Williams 2008); stigma of being a victim of violence (Ahmad, Driver et al. 2009); the stigma of belonging to a marginalized racial/ethnic group (Brown, Belue et al. 2010) ; and/or the stigma of being an unmarried pregnant woman in many settings (Ellison 2003; Zwang and Garenne 2008). These types of stigma may also be compounded or “layered” with other pre-existing stigmas, such as stigmas toward same-sex partnerships, sex workers, and people who use drugs (Nyblade 2006). See Figure 3 for an example of the overlapping stigmas that may be experienced by poor women in marginalized racial or ethnic groups living with HIV.

**Figure 3: Overlapping Stigmas**



Women of reproductive age may fear or experience HIV-related stigma and discrimination in a multitude of settings and contexts in their daily lives—in their intimate partner relationship(s), in their family, in the community, at work, and in healthcare services. Self (or internalized) HIV-related stigma is another important force that negatively affects women’s quality of life, healthcare utilization, and mental health (Simbayi, Kalichman et al. 2007; Kalichman, Simbayi et al. 2009; Rahangdale, Banandur et al. 2010; Vyavaharkar, Moneyham et al. 2010). Pregnant women have become especially vulnerable to stigma and discrimination, as maternity services have now become prime locations for HIV testing and provision of PMTCT interventions, especially in the sub-Saharan African countries with the highest HIV prevalence. Thus, all pregnant women in these countries become aware that they will have to deal with the issue of HIV when visiting maternity services. Box 1 illustrates some of the dimensions of HIV-related stigma and discrimination commonly experienced by pregnant women.

### Box 1. Examples of HIV-Related Stigma and Discrimination Experienced by Pregnant Women

**Anticipated stigma:** Pregnant women may avoid seeking antenatal care or labor and delivery services during pregnancy if they fear HIV testing and anticipate stigma if found to be HIV positive.

- A focus group discussion participant in Soweto reported, “I didn’t book at an antenatal clinic because I was afraid that they would test me for HIV, so I avoided it as I told myself that I might be found to have this disease” (Laher, Cescon et al. 2011).

**Perceived community stigma:** HIV-positive pregnant women may avoid PMTCT services and HIV treatment for their own health if they perceive that women living with HIV in their community experience stigma and discrimination if they use HIV-related services.

- In a study of 28 participants in a PMTCT program in Malawi, half dropped out citing “involuntary HIV disclosure and negative community reactions, unequal gender relations, difficulties accessing care and treatment, and lack of support from husbands” (Chinkonde, Sundby et al. 2009).

**Self-stigma:** HIV-positive women who blame themselves and internalize negative perceptions about people living with HIV may be less likely to enroll in HIV care and treatment for their own health and may suffer from depression.

- Among HIV-positive women in Karnataka, India, “...self-stigma was in many cases derived from moral judgment of one’s self for not fulfilling traditional gender roles of wife and mother” (Rahangdale, Banandur et al. 2010).

**Enacted stigma:** Pregnant women or women who wish to become pregnant, who disclose their HIV-positive status (either advertently or inadvertently) may be physically or verbally abused or socially isolated.

- In Mexico, a young woman related the following experience: “The doctor said: ‘How can you even think about getting pregnant knowing that you will kill your child because you’re positive?!!!’ He threatened not to see me again if I got pregnant. He told me that I was ‘irresponsible,’ a bad mother, and that I was certainly running around infecting other people” (Kendall 2009).

In response to this situation, we reviewed the existing academic and programmatic literature to examine the current evidence on stigma and discrimination and their negative impacts on PMTCT and family health. As part of this review, the team examined how stigma and discrimination act as barriers at each step in the complex series of interventions that women and infants must complete for successful PMTCT (characterized as “the PMTCT cascade”). The team also explored how and whether the integration of PMTCT, ANC, and MNCH services may mitigate the negative effects of stigma and discrimination. The data were then used to develop recommendations for programmatic actions to integrate strategies aimed at the reduction of stigma and discrimination into PMTCT and ANC and MNCH services.

### III. METHODOLOGY

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The Health Policy Project team conducted a strategic literature review and scan of both peer-reviewed and grey literature. This included searches using Scopus and PubMed focusing on three key areas: stigma and discrimination as a barrier to PMTCT and retention in the PMTCT cascade, integration of PMTCT with ANC and MNCH services and stigma and discrimination, and interventions to reduce stigma and discrimination. The range of key search terms focused on PMTCT, the specific steps in the PMTCT cascade, stigma, discrimination, loss to follow-up, adherence, integration of PMTCT with ANC and MNCH, and stigma-reduction interventions.<sup>1</sup> To ensure a comprehensive literature review, no date restrictions were put on the search.

The initial Scopus search using the full set of search terms returned 1,599 articles; the PubMed search returned a sub-set of these same articles. To examine the role of stigma and discrimination in PMTCT service utilization, this set of articles was then initially reviewed for the following criteria: (1) explicit analysis of stigma and discrimination as qualitative measures or quantitative constructs; (2) examination of a specific step in the PMTCT cascade; and (3) exploration of stigma and discrimination as related to PMTCT or Maternal health. In addition, our review focused on literature from low-resource settings in developing countries. If articles did not meet these criteria, they were then excluded from the review. Additional articles were added to the analysis based on a scan of selected articles' reference lists and reviewed with the same criteria. Further papers were attained from a grey publication search that included program evaluation reports, white papers, and presentations identified through searching the websites of organizations involved in PMTCT service provision or focused on stigma and discrimination, including the Stigma Action Network (SAN), World Health Organization (WHO), United Nations Children's Fund (UNICEF), United Nations Program on HIV/AIDS (UNAIDS), and The Elizabeth Glaser Pediatric AIDS Foundation.

The final review includes findings from 150 documents mainly from peer reviewed journals, agency (e.g., UN), or project reports. Of the journal articles, the majority presented qualitative data (55), with 26 articles presenting quantitative data, 14 using mixed methods, and 11 presenting literature reviews. Agency or program reports also comprised a substantial portion of the documents cited (37).

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<sup>1</sup> Specific search terms used included stigma and PMTCT, discrimination and PMTCT, stigma and PMTCT adherence, PMTCT adherence and stigma and discrimination, maternal health and stigma and discrimination, PMTCT cascade, PMTCT adherence, PMTCT and loss to follow-up, antenatal HIV testing, antenatal HIV testing and PMTCT adherence, barriers to PMTCT, HIV testing and cascade, adherence and infant testing, adherence and infant testing and HIV, loss to follow-up and HIV and pregnant women, people living with HIV and pregnant women, AZT adherence, PMTCT uptake and stigma, integration and PMTCT and ANC, integration and PMTCT and maternal, integration and HIV and ANC, intervention and stigma and pregnant women, PMTCT and stigma and reduction, stigma reduction and best practices, stigma intervention and HIV and best practices, stigma intervention and HIV and policy, stigma intervention and HIV and pregnant women.

## IV. RESULTS

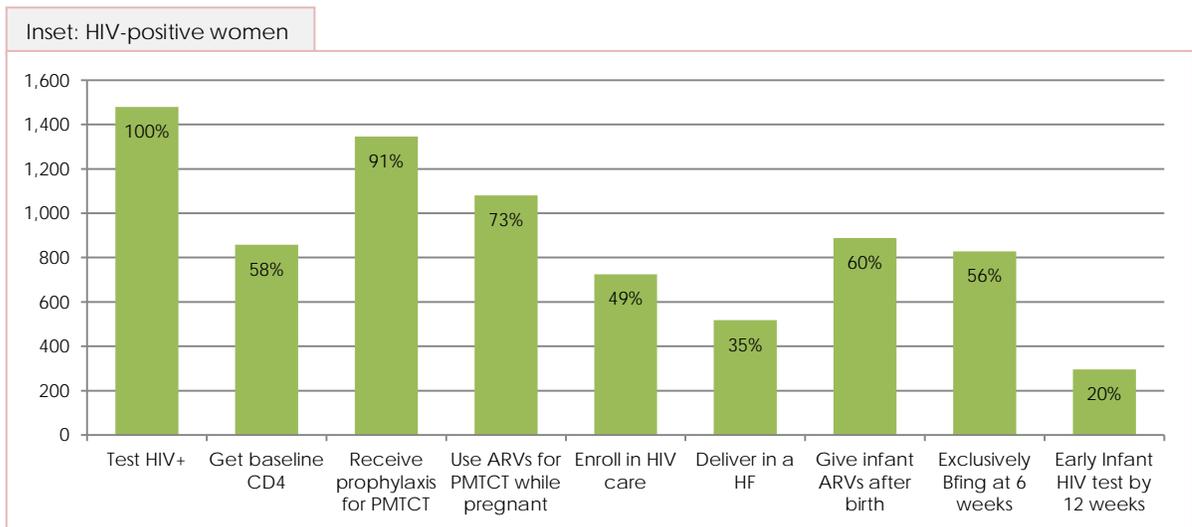
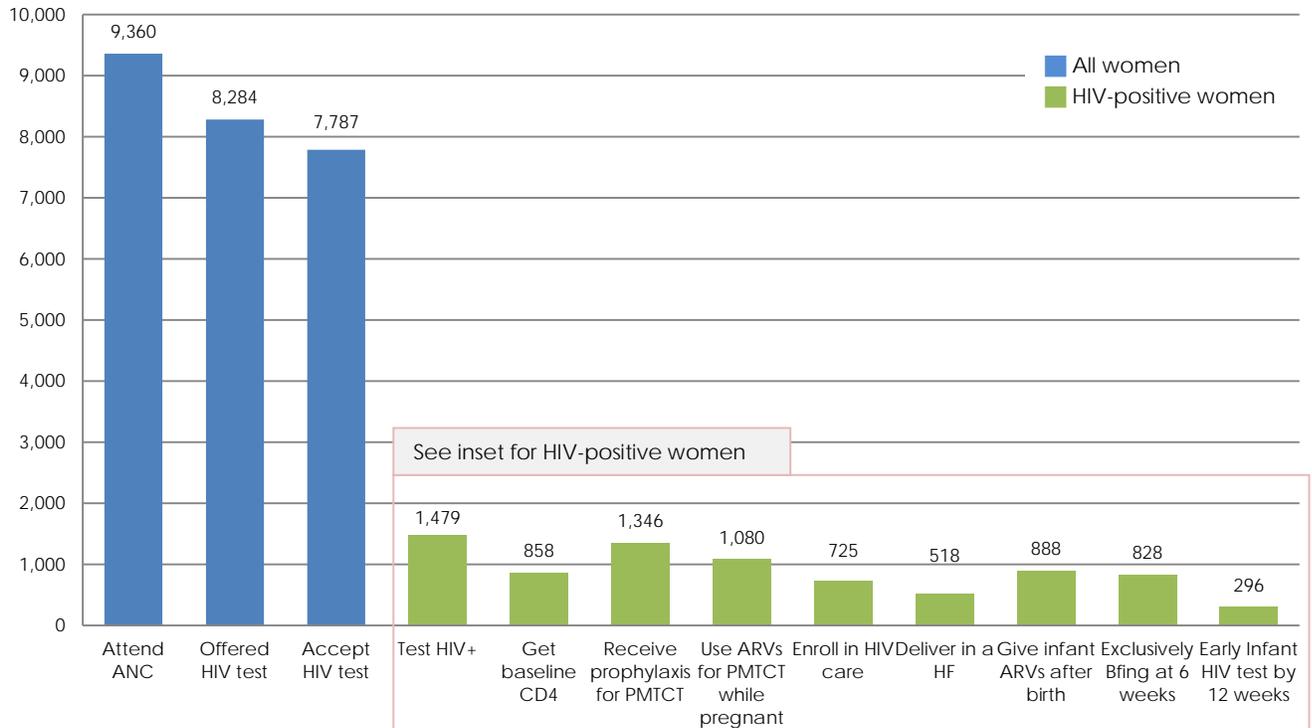
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### Stigma, Discrimination, and the PMTCT Cascade

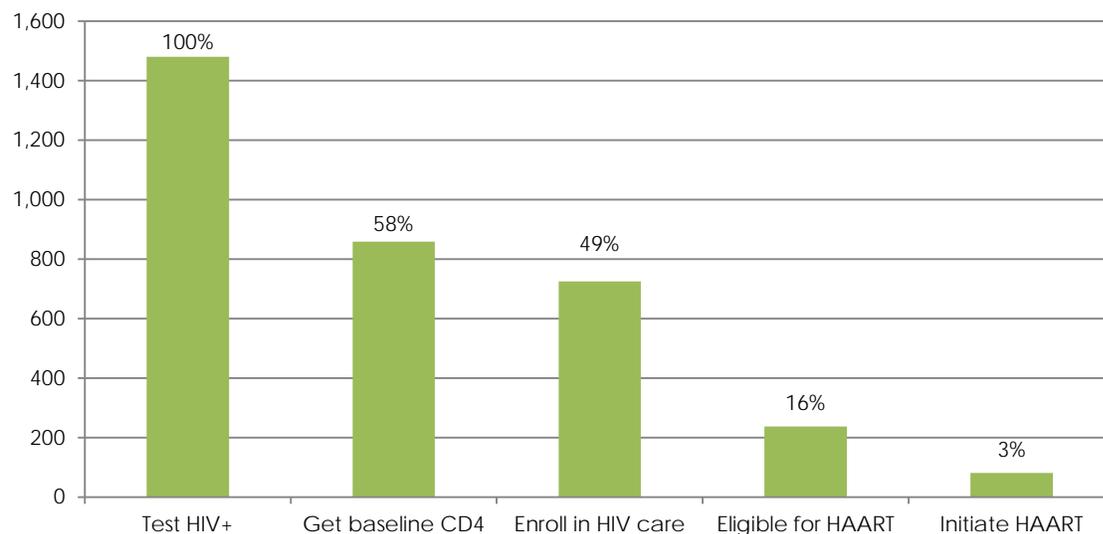
There are important drop-offs in women's use of PMTCT services at each step of the PMTCT cascade. Despite the important advances in ART regimens for maternal health and PMTCT and PMTCT service provision in many countries, women are continuing to die and infants continue to contract HIV, leading to illness and death. This situation appears to be driven by low use of known, effective (and often available) interventions for PMTCT in many settings. Data from various countries show large drop-offs in uptake and retention in PMTCT services at each step in the complex PMTCT cascade (Sripipatana, Spensley et al. 2007; World Health Organization, UNAIDS et al. 2009; Torpey, Kabaso et al. 2010). Figure 4 shows estimates of the number of women completing each step of the PMTCT cascade in Rural South Nyanza Province, Kenya, from 2008–2011. The figure illustrates the challenges faced in retaining women across the cascade.

Although great strides in antenatal HIV testing have been achieved (Byamugisha, Tumwine et al. 2010; WHO, UNAIDS et al. 2011)—and the introduction of rapid testing in many settings has virtually eliminated the gap between those pregnant women accepting testing for HIV and those receiving their HIV test results—the largest drop-offs in this PMTCT cascade now come *after* an HIV-positive test result, in women's linkage with and retention in PMTCT and HIV care (Manzi, Zachariah et al. 2005; Stringer, Chi et al. 2008; Stringer, Ekouevi et al. 2010; Ferguson L, Grant AD et al. 2012). Figure 5 illustrates this challenge for pregnant women who test HIV positive in Rural South Nyanza Province. New service initiatives—such as “Option B-plus,” in which all HIV-positive pregnant women are recommended to start on highly active antiretroviral therapy (HAART) and be kept on treatment for life (Alcorn 2010)—and point-of-care CD4 testing (Jani, Siteo et al. 2011) could potentially result in further reductions in drop-offs in the cascade, but they also bring new challenges in terms of adherence and retention.

**Figure 4: PMTCT Cascade Estimates for Rural South Nyanza Province, Kenya, 2008–2011** for a hypothetical cohort of 10,000 women\*



\*Estimates were made using data from Family AIDS Care and Education Services (FACES) program (FACES 2012), the Kenya Demographic and Health Survey 2008–2009 (Kenya National Bureau of Statistics and IFC Macro 2010), and the Maternity in Migori and AIDS Stigma Study (Turan et al., 2011).

**Figure 5: HIV Care and Treatment Cascade for Pregnant and Postpartum Women**

\*Estimates were made using data from Family AIDS Care and Education Services (FACES) program (FACES 2012), the Kenya Demographic and Health Survey 2008–2009 (Kenya National Bureau of Statistics and IFC Macro 2010), and the Maternity in Migori and AIDS Stigma Study (Turan, Onono et al. 2011).

**Stigma, discrimination, and related lack of disclosure of status within the couple are key barriers to PMTCT uptake and drivers of loss to follow-up.** Multiple reports and studies conducted in various country sites show that fears and experiences of stigma and discrimination from the community, family, and health workers are among the most important barriers to pregnant women’s acceptance of HIV testing during antenatal care (Kilewo, Massawe et al. 2001; Pool, Nyanzi et al. 2001; Rogers, Meundi et al. 2006; Larsson, Waiswa et al. 2009; Turan, Bukusi et al. 2011), their initial participation in programs for PMTCT (Ekouevi, Leroy et al. 2004; Painter, Diaby et al. 2005), and their retention and adherence in these programs (Painter, Diaby et al. 2004; Bwirire, Fitzgerald et al. 2008; Rahangdale, Banandur et al. 2010; Awiti Ujiji, Ekstrom et al. 2011; Mepham, Zondi et al. 2011). These studies have explored pregnant women’s experiences from their own perspectives and those of their family members and have revealed the important role that fears of HIV-related stigma and discrimination play in discouraging pregnant women’s use of both HIV-related and non-HIV-related health services. Some authors also point out that PMTCT programs themselves—due to lack attention to privacy and confidentiality—may cause pregnant women to suffer from HIV-related stigma and discrimination (Thorsen, Sundby et al. 2008).

HIV-related stigma and discrimination have consequences for healthcare workers who provide services to pregnant women as well. Due to the high level of contact with blood and bodily fluids, healthcare workers on labor and delivery wards are particularly prone to fears of HIV infection and related stigma and discrimination, which may translate into reduced initiation of or adherence to maternity and PMTCT services by pregnant women (Turan, Bukusi et al. 2008).

Pregnant women are often placed in an untenable dilemma in which they are forced to choose between immediate threats to their social, economic, and physical well-being if their HIV status is disclosed and the future health benefits for themselves and their unborn child in utilizing PMTCT.

Fears of disclosure and non-disclosure appear to be key mechanisms through which stigma and discrimination operate as barriers to use of PMTCT and maternity services. Disclosure of HIV status can have important benefits, including gaining access to social support, lowering the risk of HIV transmission to partners, gaining direct health benefits, obtaining more appropriate medical treatment, decreasing stress, and creating closer relationships with others (Greene, Derlega et al. 2003). For pregnant women, lack of disclosure of HIV status within the couple limits their ability to link and adhere to HIV care for their own health and PMTCT, as well as posing a risk for sexual transmission of HIV where the male partner is still HIV negative (Orne-Gliemann and Desgrées-Du-Lou 2008; Desgrées-du-Loû , Brou et al. 2009; Katz, Kiarie et al. 2009; Bond 2010). However, pregnant women in many settings fear and experience real threats to their health and well-being associated with disclosure of their HIV-positive status (Medley, Garcia-Moreno et al. 2004; Medley, Kennedy et al. 2009; Obermeyer, Baijal et al. 2011), including intimate partner violence (Dlamini, Kohi et al. 2007).

## **How Stigma and Discrimination Impact Each Step in the PMTCT Cascade**

The literature review yielded a wealth of qualitative studies and a more limited number of quantitative studies from different settings worldwide that examined how stigma and discrimination affect each step in the PMTCT cascade (see Annex B for a summary table).

### ***Initiating use of ANC***

Qualitative data suggest that fears of HIV testing, unwanted disclosure, and resultant stigma and discrimination may cause some women to avoid ANC services all together (Turan, Miller et al. 2008; Rahangdale, Banandur et al. 2010; Laher, Cescon et al. 2011), at the very beginning of the cascade. This finding is difficult to capture, since most studies are done with populations of pregnant women already attending antenatal care. If women perceive that they will be forced to test for HIV (Ujiji, Rubenson et al. 2011) or fear lack of confidentiality of HIV test results at the health facility, they may decide to forgo ANC visits all together or try to find a clinic that does not emphasize HIV testing of pregnant women. For example, in one community in rural Kenya, it became known that a nearby mission hospital was not requiring HIV testing of pregnant women. Subsequently, most pregnant women in the community stopped going to the government clinic and went to the mission hospital instead to avoid HIV testing. In this case, pregnant women failed to learn their HIV status and could not take advantage of PMTCT interventions (personal communication, Dr. Maricianah Onono).

### ***Being offered an HIV test***

Beyond the health system barriers to offering an HIV test in ANC (lack of test kits, workers not trained, or other systemic breakdowns), there is the potential for health workers' stigmatizing attitudes and stereotypes about who is at risk of HIV to affect who is offered HIV testing, resulting in some types of pregnant women not even being offered the test (Rakgoasi 2005) or others being tested without their consent (Oosterhoff, Hardon et al. 2008; Turan, Miller et al. 2008). However, the routinization of antenatal HIV testing and the use of opt-out approaches have reduced considerably the drop-off at this stage in the PMTCT cascade.

### ***Accepting HIV testing***

At the next step, there are both qualitative and quantitative data indicating that fears of stigma and discrimination may lead some pregnant women to refuse antenatal HIV counseling and testing when offered (Shetty, Marangwanda et al. 2008). In rural Kenya, pregnant women who reported in an interview conducted before an antenatal visit that they anticipated male partner stigma if testing HIV positive were more than two times more likely to refuse HIV testing during the ANC visit than other women, after adjusting for other factors associated with testing uptake (Adjusted OR=2.10; 95% CI=1.15-3.85) (Turan,

Bukusi et al. 2011). In South Africa, pregnant women with low “HIV testing attitude” scores (which contained items such as “My friends would look down on me if I were tested for HIV”) were significantly less likely to accept post-test counseling for HIV (OR =0.96; 95% CI=0.93-0.98) (Peltzer, Mlambo et al. 2010). However, there are also data suggesting that in the current era of opt-out testing, pregnant women are less likely to refuse HIV testing (Kinuthia, Kiarie et al. 2011), potentially related to the fact that many women may not understand that they can actually refuse HIV testing (Ujiji, Rubenson et al. 2011; Hardon, Vernooij et al. 2012).

### ***Enrolling in PMTCT or HIV treatment services***

The next step where HIV-related stigma and discrimination may play a role is when women decide whether to participate in PMTCT and HIV treatment programs after testing HIV positive during ANC. In many cases, women may defer to enroll at the time of HIV testing, often citing a need to go home and confer with their husband, and then never return to the health facility due to fears of HIV-related stigma and discrimination. Although many ANC clinics provide women with all the ART drugs needed for both mother and infant for PMTCT prophylaxis at the time of the initial HIV-positive test result (in case they never come back to the clinic), little is known about whether women are actually able to adhere to those medications. After testing HIV positive and being offered PMTCT services in the ANC clinic, in many settings, women (especially those who are sicker, indicated by a low CD4 count or advanced stage of HIV disease) will also need to visit a separate HIV clinic (or at least go through an additional process) to “enroll in HIV care and treatment” in order to receive HAART (for both PMTCT and maternal health) and other specialized care. In one study in Nairobi, stigma was the most commonly cited barrier for HIV-positive pregnant women’s failure to enroll in HIV care (77%) (Otieno, Kohler et al. 2010). In rural Nyanza, Kenya, pregnant women with high levels of internalized HIV-related stigma<sup>2</sup> were much less likely to enroll in HIV care after testing in ANC than those with low levels of internalized HIV-related stigma (OR=.54, 95% CI: .34-.86)(Turan, Onono et al. Forthcoming). In Zimbabwe, stigma indicators (e.g., ever been stigmatized, witnessed someone being stigmatized) were not significantly related to pregnant women’s enrollment in HIV care (confidence intervals for ORs included 1.0), although the authors noted that more than two-thirds of the women in the sample were enrolled in psycho-social support groups that may have helped them cope with HIV-related stigma (Muchedzi, Chandisarewa et al. 2010).

### ***Adhering to ART and follow-up visits during pregnancy***

Even if women do enroll in PMTCT programs or HIV care, fears of unwanted disclosure, stigma, and discrimination may make it difficult for them to adhere to ART prophylaxis or HAART during pregnancy. Adherence becomes difficult if women need to hide HIV clinic visits or medications from others (Kunihira, Nuwaha et al. 2010). In qualitative research in Kenya, both urban and rural women described the need to take measures to assure that family and neighbors did not find out about their HIV-positive status during pregnancy, and that this adversely affected their PMTCT adherence (Awiti Ujiji, Ekstrom et al. 2011). In KwaZulu-Natal, South Africa, pregnant women described having to hide their PMTCT medications from boyfriends, family members, and employers (Mephram, Zondi et al. 2011). In another South African study, women who felt their HIV status was kept confidential at the health facility were significantly more likely to report adherence to single-dose nevirapine during pregnancy (Adjusted

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<sup>2</sup> Measured using the self-stigma sub-scale of the HASI-P instrument (Holzemer, Uys et al. 2007).

OR= 2.57; 95% CI=1.00–6.53) (Peltzer, Mlambo et al. 2010). The PEARL Study, which measured nevirapine levels in umbilical cord blood samples, was able to demonstrate that a substantial number of women were unable to adhere to nevirapine doses received during pregnancy (Stringer, Ekouevi et al. 2010; Kirsten, Sewangi et al. 2011).

### ***Giving birth with a medically trained attendant***

Childbirth with a skilled, medically-trained professional—which is most likely to be available when women deliver their babies in a health facility—has been identified by the World Health Organization as a major priority for preventing maternal and infant mortality (WHO 2002; Stanton, Blanc et al. 2006). Beyond the issue of HIV, maternal survival is critical for the health of infants and children. There is also emerging evidence that skilled delivery assistance enhances the effectiveness of PMTCT interventions, as women who give birth with the assistance of a health professional have an additional opportunity for HIV testing and, if HIV positive, may be more likely to use antiretroviral drugs for PMTCT meant to be taken around the time of delivery (Sripipatana, Spensley et al. 2007; Ndirangu, Newell et al. 2010; Kinuthia, Kiarie et al. 2011). Qualitative studies have revealed that fears about HIV-related stigma may cause some women to avoid facility-based delivery (Turan, Miller et al. 2008; Awiti Ujiji, Ekstrom et al. 2011), and one study in rural Kenya found that pregnant women who held stigmatizing and discriminatory views about people living with HIV were less likely to deliver in a health facility, even after controlling for a variety of factors known to be associated with facility-based delivery (Adjusted OR=0.44, 95% CI:0.22-0.88) (Turan, Hatcher et al. Forthcoming (a)). HIV-positive women who had disclosed their HIV status to anyone were 6.5 times more likely to deliver in a health facility than HIV-positive women who had not disclosed to anyone, even after controlling for other factors associated with childbirth in a health facility (Adjusted OR=6.53; 95% CI: 2.45-17.44) (Turan, Onono et al. 2011).

### ***Adhering to recommended infant feeding practices***

After the birth, women may be reluctant to use recommended infant feeding practices for PMTCT (namely formula feeding or exclusive breastfeeding up to 6 months of age) if they are different than those used in the community (Eide, Myhre et al. 2006; Buskens, Jaffe et al. 2007; Morgan, Masaba et al. 2010). Women may fear that following an infant feeding mode that is not the cultural norm or standard (e.g., exclusive breastfeeding) will lead to disclosure of their HIV-positive status and trigger stigmatization and discrimination (Desclaux and Alfieri 2009; Sibeko, Coutoudis et al. 2009). As recommended infant feeding guidelines and practices for HIV-positive mothers become more widely known, exclusive breastfeeding may become a marker for HIV infection. In Kenya, HIV-positive women who had already disclosed their HIV status were significantly more likely to be practicing exclusive breastfeeding at 4-8 weeks after the birth than other women ( $p=.003$ ) (Turan, Onono et al. 2011).

### ***Adhering to maternal and infant follow-up visits and antiretrovirals (ARVs) after the birth***

After the birth, fears of stigma and discrimination can again be barriers to adherence to ART for the infant or the mother due to the need to hide visits and/or medications from others (Peltzer, Mlambo et al. 2010; Laher, Cescon et al. 2011). Among mothers living with HIV interviewed in a study in Kenya, women who thought that people living with HIV should be ashamed (internalized stigma) were much less likely to report having used ARVs than women who did not agree with this statement (OR = 0.22, 95% CI: 0.08-0.62,  $p = 0.004$ ) (Kinuthia, Kiarie et al. 2011). This step of adherence gains great importance in the face of the latest recommendations for continuing ARVs for mothers and infants throughout breastfeeding and longer.

### ***Bringing infant for HIV testing***

Similar factors related to HIV stigma have been shown to come into play in parents' use of infant HIV testing services (Kiragu, Schenk et al. 2008). In South Africa, although HIV stigma and discrimination

scores were not significantly associated with uptake of infant testing, women who had shared their HIV test result with someone were 2.51 times more likely to have had their infant tested for HIV than those who had not shared with anyone (95% CI=1.49–4.22) (Peltzer and Mlambo 2010). In Mozambique, researchers attributed the association between HIV-positive women’s greater distance from the hospital and early infant diagnosis to the decrease in stigma associated with seeking HIV care outside of one’s own community (Cook, Ciampa et al. 2011). On the other hand, a study in Kenya found that selected measures of HIV-related stigma were not significantly associated with infant testing uptake (Kinuthia, Kiarie et al. 2011).

## **The Cumulative Effects of Stigma and Discrimination Across the PMTCT Cascade**

The effects of stigma and discrimination are cumulative across the PMTCT cascade and therefore may significantly impact rates of infant HIV infection. As demonstrated in these studies, stigma and discrimination can have a negative impact at each stage of the PMTCT cascade—from the first steps of attending ANC and accepting an HIV test through to infant feeding and treatment—adding up to a potentially substantial negative impact on uptake of and retention of PMTCT services. Recent work to model the impact of stigma and discrimination on vertical transmission and PMTCT programs (Watts, Zimmerman et al. 2010; Prudden, Dzialowy et al. Forthcoming, 2012) has shown that the cumulative effect could be substantial.

For Johannesburg, South Africa, Prudden and colleagues (2012) estimate that 44 percent of all vertical HIV transmissions may be averted if stigma and discrimination could be reduced from a high to a minimal level, with an inter-quartile range estimate of 38–46 percent. Similarly, Watts and colleagues (2010), modelling generic scenarios for PMTCT programs using single-dose Nevirapine as the standard of care, estimated that stigma and discrimination might be responsible, depending on the strength of the healthcare setting, for between 26 percent and 53 percent of infant HIV infections and that a highly effective stigma reduction program could reduce infant HIV infections by as much as 33 percent.

## **Integration of ANC/MNCH/FP and HIV Services: Will it Remove Stigma and Discrimination (S&D) as a Barrier to PMTCT and Cause of Loss to Follow-Up?**

Integration of HIV and reproductive health services (including ANC, MNCH, and family planning) is a promising strategy to overcome some of the barriers to successful completion of the PMTCT cascade and to help ensure that women and their families receive the full range of needed health services. Definitions of “integration” vary, ranging from HIV counseling and testing and basic PMTCT services in antenatal clinics (already the standard in most settings) to full integration of comprehensive HIV services (including HAART) for pregnant and postpartum women, their partners, and their infants into ANC and MNCH services (The President’s Emergency Plan for AIDS Relief (PEPFAR) 2011). In a fully integrated model, HIV-positive pregnant and postpartum women can receive comprehensive HIV care and treatment from their ANC healthcare provider during their ANC clinic visit, including opportunistic infection prophylaxis, tuberculosis (TB) diagnosis and treatment, WHO clinical staging for HIV, HAART, CD4 count monitoring, relevant laboratory tests (such as complete blood counts, creatinine, liver enzymes, etc.), adherence counseling, peer education, and access to support groups (Turan, Steinfeld et al. Forthcoming).

Experiences in several sub-Saharan African settings suggest that integrating ANC, MNCH, PMTCT, and HIV care may result in better uptake of services, (Horwood, Haskins et al. 2010; Torpey, Kabaso et al. 2010; Tsague, Tsiouris et al. 2010), more women receiving counseling (Welty, Bulterys et al. 2005),

reduction of the time to treatment initiation (van der Merwe, Chersich et al. 2006; Killam, Tambatamba et al. 2010), improved quality of care (Delvaux, Konan et al. 2008; van den Akker, Bemelmans et al. 2012), and potentially reduction of stigma (Bond, Chase et al. 2002; Etiebet, Fransman et al. 2004; Sherr 2012). There is also evidence that integration is associated with increased satisfaction with ANC visits for HIV-positive women ( $p=.044$ ), without adversely affecting satisfaction for HIV-negative women (ns) (Vo, Cohen et al. 2012).

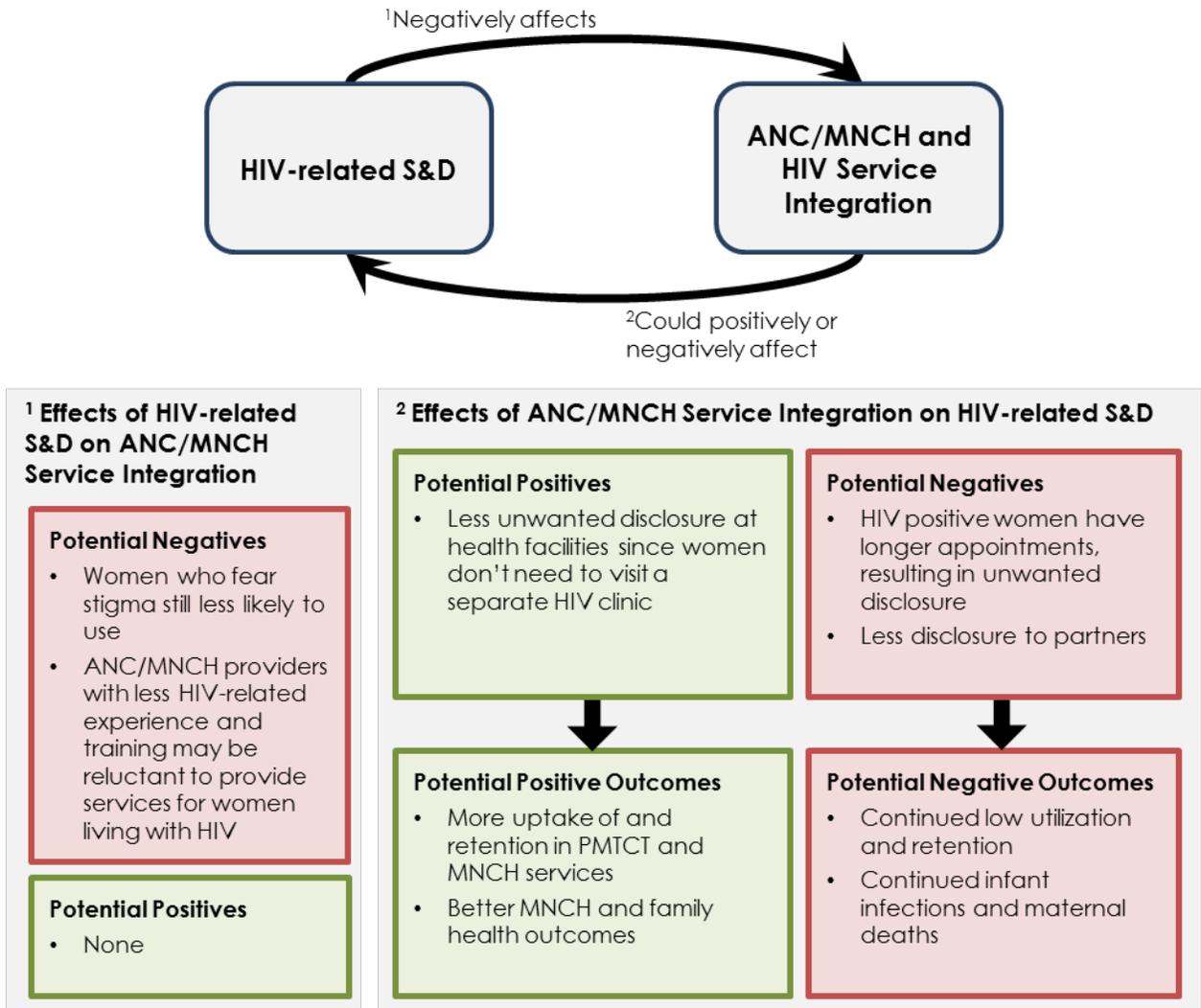
Based on these reports, many countries and programs have begun efforts to fully integrate HIV and reproductive health services (Fleischman 2011), and the U.S. President's Emergency Plan for AIDS Relief has allocated special funds in six high-burden countries to "accelerate integration" of PMTCT with MNCH, FP, other HIV programs (Reeves 2011). Although the overall evidence-base for integration is still relatively weak due to the lack of controlled trials (Tudor Car, van-Velthoven et al. 2011; Sherr 2012), recent systematic reviews of MNCH, FP, and HIV integration intervention studies have found that integration is feasible and that the majority of studies report positive effects on outcomes (Kennedy, Spaulding et al. 2010; Brickley, Almers et al. 2011).

Despite the great promise of integration, there is also evidence that integrating clinical services may not be enough to address some of the barriers to full use of PMTCT and HIV treatment services for women, partners, and infants. In Zambia, integration of ANC and HIV services doubled the proportion of treatment-eligible women enrolling in HIV care (Adjusted OR=2.06; 95% CI: 1.27-3.34), as well as doubled the proportion of treatment-eligible women initiating ART while pregnant (Adjusted OR=2.01; 95% CI=1.37-2.95). However, even with integration, the proportions of women enrolling in care (44.4%) and successfully initiating ART while pregnant (32.9%) remained unacceptably low (Killam, Tambatamba et al. 2010). In South Africa, after integration, only 75% of ART eligible women initiated treatment (van der Merwe, Chersich et al. 2006). Preliminary findings from the Maternity in Migori and AIDS Stigma (MAMAS) Study in Kenya—conducted at the same sites as a cluster randomized trial of ANC and HIV treatment service integration—indicate that HIV-related stigma continues to be an important barrier, even in fully integrated service settings. Of HIV-positive pregnant women enrolled in the MAMAS prospective cohort, only 51 percent had enrolled in HIV care by six weeks after the birth. Those women with high levels of internalized HIV-related stigma were much less likely to enroll in HIV care than those with low levels of internalized HIV-related stigma, regardless of the service integration status of the site (OR=0.54, 95% CI: 0.34-0.86)(Turan, Onono et al. Forthcoming).

Although it is often assumed that service integration will result in fewer fears and experiences of HIV-related stigma and discrimination for pregnant and postpartum women, as a pregnant woman's HIV status would remain more confidential if she does not have to visit a separate HIV clinic, this remains to be seen. Some studies have suggested that the integration of PMTCT into antenatal care may result in increased fears of stigma (Sherr 2012). In addition, although integration might reduce women's fears and experiences of HIV-related stigma and discrimination related to unwanted disclosure, integration might actually introduce new opportunities for unwanted disclosure and thereby potential for stigma and discrimination. For example, healthcare providers in Kenya suggested that integration might result in unwanted disclosure of HIV status in the ANC clinic if HIV-positive women have longer appointments than other women (Winestone, Bukusi et al. 2011). Alternatively, they worried that increased confidentiality of HIV status in the ANC clinic setting would allow more women to avoid HIV status disclosure to their male partners, with negative effects on their subsequent uptake and adherence to PMTCT and other HIV services, as well as posing a risk of HIV transmission to male partners who are still HIV negative. It does appear that women may be less likely to disclose after testing for HIV in ANC clinics, as opposed to after testing in free-standing voluntary counseling and testing centers (Medley, Garcia-Moreno et al. 2004).

Looking at the other side of the coin, it is important to consider how continuing HIV-related stigma and discrimination might affect the success of integrated services. It is possible that ANC health workers, who generally have less formal training in psychosocial aspects of HIV than workers in specialized HIV clinics, may hold stigmatizing and discriminatory beliefs about women living with HIV and refuse to treat or neglect such patients. At one site, randomized to the fully integrated arm in the Study of HIV and Antenatal care Integration in Pregnancy (SHAIP) trial in Kenya (Turan, Steinfeld et al. Forthcoming), one ANC nurse initially refused to provide services to HIV-positive women and sent them away (Turan, personal communication). Another possibility could be that women's fears of HIV-related stigma might make them avoid integrated ANC clinics and maternity wards all together if they become known in the community as sites where HIV care and treatment are delivered (Turan, Hatcher et al. Forthcoming (b)) . A qualitative study in Eastern Uganda found that the negative effects of stigma and lack of service integration came together when newly tested HIV-positive women avoided specialized HIV clinics that were better stocked and prepared to provide PMTCT and HIV services (Rujumba, Tumwine et al. 2012). Figure 6 illustrates the potential ways that integration may affect stigma and discrimination and vice versa.

**Figure 6: Potential Relationships of HIV-related S&D and Service Integration**



## V. RECOMMENDATIONS

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This review suggests that integrated reproductive health and HIV services will not reach their full potential to save lives without addressing the context of women’s lives and, in particular, the continuing threats of stigma and discrimination associated with HIV-positive status in so many countries. Fortunately, effective strategies and tools to reduce and measure HIV-related stigma have been developed and are available and can be included as an integral part of PMTCT and HIV services.

The goals of virtual elimination of vertical transmission and reduction of HIV-related maternal mortality will be impossible to reach without addressing the real context of women’s lives and, in particular, lowering the barriers of stigma and discrimination. Integration of PMTCT and other HIV services into MNCH and other reproductive health services may be part of the solution but will likely not be enough. Along with important modifications to make clinical services more effective, convenient, and accessible for pregnant women, there is also a need to integrate HIV-related stigma and discrimination reduction components into PMTCT and MNCH services.

The good news is that actions can be taken—there are existing stigma and discrimination reduction tools and intervention models, as well as measures to evaluate progress that can be easily integrated into PMTCT and MNCH programs. Programs globally are beginning to identify a variety of effective HIV-related stigma-reduction strategies (Nyblade, Stangl et al. 2009; Carr, Eckhaus et al. 2010; Pulerwitz, Michaelis et al. 2010; Sengupta, Banks et al. 2011). Below, we identify a few examples of key steps and strategies for the integration of stigma-reduction into PMTCT and MNCH programs and service settings that can be implemented by policy leadership at the global and national levels, by administrators and health workers at the health facility level, and by programs that work with clients and their communities.

### Global and National Policy Level

Ensure that global campaigns identify and fund S&D reduction as a key strategy for success. Global campaigns for the virtual elimination of child HIV infection and reduction in maternal mortality should identify S&D reduction as key strategy to meeting global goals and include S&D reduction in technical program guidance for PMTCT. Specifically, global campaigns should support the operationalization of S&D reduction, set measurable S&D reduction targets, and include guidance for measuring, monitoring, evaluating S&D reduction efforts.

Adopt national policies and strategies. At the national level, strategies and operational plans can include programs and approaches to support facilities, healthcare providers, people living with HIV, and key affected populations to reduce stigma and discrimination for PMTCT and maternal health programs. Commitment at the national level to have all health services be “free of HIV-related stigma” could support a broad range of technical and programmatic interventions to have better health outcomes, including more successful PMTCT outcomes.

In addition, media channels—such as television, radio, the Internet, and posters/billboards—can be considered to show that HIV affects “people like us” and give the epidemic a human face (Pulerwitz, Michaelis et al. 2010). Programs such as “Siyayinqoba Beat It!” in South Africa (Community Media Trust 2011) have featured the stories of pregnant women living with HIV. However, while qualitative research with women attending PMTCT services in South Africa revealed that such media attention around HIV and PMTCT could have positive effects—in the form of helping to facilitate wanted disclosure—it can also have negative effects, by causing unwanted disclosure and stigma by creating a public association between HIV and certain maternal and child health practices (i.e., exclusive breastfeeding) (Varga, Sherman et al. 2006). In Kenya, PMTCT media campaigns emphasizing the importance of childbirth in a health facility for HIV-positive pregnant women may have inadvertently

strengthened the image that a health facility birth is something only for women with complications or illnesses like HIV (Medema-Wijnveen J, Onono MA et al. Forthcoming). Thus, we recommend that any PMTCT media campaigns be designed with the participation and input of advocacy groups and HIV-positive pregnant women.

## Health Facility Level

Help institutions that serve pregnant and postpartum women recognize how stigma and discrimination affects their clients. A first step in addressing HIV-related stigma and discrimination is often to get healthcare providers and health administrators to recognize that people living with HIV experience stigma and discrimination in health facilities (Mahendra, Gilborn et al. 2006; Khuat Thi Hai, Pham Duc et al. 2008; Nyblade, MacQuarrie et al. 2008; Kendall 2009) In the case of PMTCT, collecting and sharing data on stigma and discrimination collected from ANC, MNCH, FP, and labor and delivery healthcare providers, as well as from HIV-positive pregnant women, can be a catalyst for interventions to reduce stigma in the healthcare setting and get providers to be aware of how fears of stigma and discrimination impact the women and families that they serve and ultimately affect uptake of services and prevention of infant HIV infections.

Program stigma-reduction into ANC, MNCH, FP, and labor and delivery (L&D) health service settings. Once healthcare providers and managers become aware of the presence of stigma and discrimination, a variety of tools and evidence-based interventions are available to help reduce stigma in the healthcare setting. Training modules for health workers on stigma, discrimination, and gender-based violence are available (EngenderHealth 2004; Kidd, Prasad et al. 2007; Khuat Thi Hai, Pham Duc et al. 2008; Turan, Hatcher et al. Forthcoming (b)) and can be incorporated into pre-service and in-service training of primary healthcare workers, including those working in ANC, MNCH, FP, and L&D clinics. There is evidence from research that such HIV stigma-reduction interventions with health workers—including methods such as participatory small group activities and having healthcare providers work collaboratively with PLHIV to understand and reduce stigma—can have a real impact on healthcare provider attitudes and behavior (Khuat Thi Hai, Pham Duc et al. 2008; Wu, Li et al. 2008; Uys, Chirwa et al. 2009).

Develop and implement policies that address the concerns of health workers in maternity care. Interventions can be implemented to address the special concerns of health workers in maternity care, including measures to ensure the safety of healthcare providers who have extensive contact with bodily fluids in settings like L&D units—including availability of protective gear and post-exposure prophylaxis—and training emphasizing universal practice of universal precautions (as opposed to selective use of universal precautions). In addition, interventions can support the development and enforcement (e.g., through a monitoring and redress system) of healthcare facility-level policies that mandate non-stigmatizing and non-discriminatory behaviors in the treatment of pregnant, childbearing, and postpartum women. Given

### Available Stigma-Reduction Tools

Understanding and Challenging HIV Stigma: Toolkit for Action (Kidd, Clay et al. 2007)

Reducing HIV Stigma and Gender Based Violence: Toolkit for Healthcare Providers in India (Kidd, Prasad et al. 2007)

Reducing Stigma and Discrimination Related to HIV and AIDS: Training for Health Care Workers (EngenderHealth 2004).

The PLHA-Friendly Achievement Checklist: A Self-Assessment Tool for Hospitals and Other Medical Institutions Caring for People Living with HIV/AIDS (PLHA) (Horizons, SHARAN et al. 2003)

Safe and Friendly Health Facility, Trainer's Guide (Khuat Thi Hai, Pham Duc et al. 2008)

For a full list of resources, visit the Stigma Action Network at [www.stigmaactionnetwork.org](http://www.stigmaactionnetwork.org).

the increased vulnerability of pregnant women to stigma, discrimination, and violence, special emphasis is needed on health facility policies for confidentiality and privacy of women's and infants' HIV status.

Routinely measure and monitor stigma and discrimination in health facilities. To support the processes recommended above, as well as the evaluation of stigma reduction interventions, routine stigma and discrimination data collection is necessary. Several studies have developed and validated scales for measuring stigma in health facilities (Stein and Li 2008; Varas-Diaz and Neilands 2008; Uys, Holzemer et al. 2009) and there is an ongoing global effort to develop, test, and standardize a shortened set of measures for stigma and discrimination in health facilities that includes a specific module focused on healthcare workers in ANC, PMTCT, MNCH, and L&D services (Nyblade and Hunger 2012).

## Client and Community Level

Create support groups to reduce the negative effects of HIV-related stigma. Research with pregnant and postpartum women worldwide shows how they are negatively affected by fears and experiences of HIV-related stigma and discrimination. Interventions can be designed using this knowledge to specifically address the expressed needs of pregnant and childbearing women, including support for safe disclosure, adherence, and reduced internalized or self-stigma, which is a major factor contributing to poor quality of life and mental health problems among HIV-positive women and men. Support groups for women and men living with HIV have been found to be beneficial. A study from rural Kenya found that support groups helped women to disclose their HIV status and provided emotional support to help cope with negative outcomes of disclosure (Gillett and Parr 2010). HIV-positive women in Zimbabwe who enrolled in an HIV support group were found to be twice as likely to access treatment as those who did not belong to any HIV support group (OR=2.34; 95% CI: 1.13-4.88) (Mucedzi, Chandisarewa et al. 2010). Interventions to specifically address internalized stigma are also being developed (Rao, Feldman et al. 2012).

Involve HIV-positive women in service delivery. Involving women living with HIV in PMTCT service delivery is a promising strategy that can empower them, improve service delivery, and contribute to stigma reduction. The mothers2mothers program, which trains new mothers living with HIV to provide education and support to other women like themselves, is an example of such a strategy that began in South Africa and is now being scaled up in eight countries in sub-Saharan Africa (mothers2mothers 2012). An evaluation of the mothers2mothers program in South Africa found that participants had greater psychosocial well-being, more use of PMTCT services, better PMTCT outcomes, and better linkage to health facilities than non-participants (Baek, Mathambo et al. 2007).

Engage the communities of pregnant women living with HIV. Changing the attitudes and behaviors of the people in women's families and communities will be essential to reduce HIV-related stigma that negatively affects women and PMTCT. Community-based, stigma reduction strategies have included forming "anti-AIDS clubs" in Zambia (Esu-Williams, Schenk et al. 2006), working with community opinion leaders in markets in China (Li, Liang et al. 2010) and local community political leaders in Tanzania (Nyblade, MacQuarrie et al. 2008), use of a range of traditional and modern entertainment methods (Stangl, Carr et al. 2010), and conducting community participation interventions in Thailand (Apinundecha, Laohasiriwong et al. 2007) and Vietnam (Nyblade, Khuat Thu et al. 2008). Although few published community-based interventions have specifically focused on PMTCT-related stigma, similar strategies could potentially be used to address community-level stigma and discrimination faced by HIV-positive pregnant women. A Rapid Results Initiative for the elimination of mother-to-child transmission in rural Kenya used focused community mobilization to create demand for and reduce stigma around PMTCT services—by engaging local opinion leaders, community health workers, and mass media on high impact days such as market days (Dillabaugh, Kulzer et al. 2012). In Kenya, a team used the results of qualitative research with pregnant women, male partners, and other family members—as well as

Stigma and Discrimination: Key Barriers to Achieving Global Goals  
for Maternal Health and the Elimination of New Child HIV Infections

feedback from community stakeholders—to develop a clinic-based, community-supported intervention that addressed risks of HIV stigma and gender-based violence experienced by pregnant women (Hatcher, Odero et al. 2011; Hatcher, Romito et al. Forthcoming; Turan, Hatcher et al. Forthcoming (b)).

Involve male partners of pregnant women in ANC and PMTCT. Given pregnant women’s fears of male partner reactions and thus their resultant lack of disclosure, programs should also include interventions that engage male partners of pregnant women in antenatal HIV testing, PMTCT, and HIV care. Indeed, couples counseling and testing strategies for pregnant women and their male partners have been successful in many settings (Farquhar, Kiarie et al. 2004; Msuya, Mbizvo et al. 2008; Becker, Mlay et al. 2009; TRAC Plus 2009). However, to date, couple counseling and testing strategies have only benefitted the minority of couples who are able to come to the clinic together. Proportions of women who actually persuaded their male partner to come into the clinic for HIV counseling and testing in various sub-Saharan African studies have ranged from 10 percent in Zambia (Semrau, Kuhn et al. 2005) to 12.5 percent in Tanzania (Msuya, Mbizvo et al. 2008) to 16 percent in Kenya (Katz, Kiarie et al. 2009). Thus, there is a need to explore community- and home-based interventions that meet men where they are and help to change stigmatizing attitudes and discriminatory and violent behaviors.

## VI. CONCLUSIONS

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It is unlikely that the global commitment to virtual elimination of vertical transmission and reduced HIV-related maternal mortality by 2015 will be met unless major efforts at the global, national, community, and facility levels are made to identify and counter the multiple manifestations of HIV-related stigma and discrimination facing pregnant women. While it has yet to be fully recognized, reducing stigma and discrimination is an essential piece of delivering care for all women, men, and children. Women of reproductive age—and especially pregnant women—are particularly vulnerable to the adverse effects of HIV-related stigma and discrimination. Furthermore, high levels of HIV-related stigma in the community and in health facilities may negatively affect all women, not just those who know they are HIV positive.

In response, global, national, district, and local health strategies and operational plans should include interventions to reduce and mitigate HIV-related stigma and discrimination in PMTCT, HIV, and MNCH services. These strategies and plans need to set targets for stigma reduction, measure the impact of stigma reduction interventions on service uptake, allocate resources (staff and financing) for interventions, and monitor the interventions and policies aimed at reducing HIV-related stigma and discrimination.

## ANNEX A. 2010 REVISED WHO PMTCT GUIDELINES

### 2010 Revised WHO PMTCT Guidelines (WHO 2010; Avert 2011)

Mother: All women identified as HIV positive during pregnancy will receive antiretroviral drugs (ARVs).		
CD4 count less than or equal to 350 cells/mm <sup>3</sup> Mother takes ARVs for her own health	CD4 count more than 350 cells/mm <sup>3</sup> Mother takes ARVs for her infant's health	
<p>A recommended course of triple ARVs to be started as soon as possible and taken indefinitely</p> <p>The preferred first-line ART regimen should include an AZT + 3TC backbone in combination with an NNRTI:</p> <ul style="list-style-type: none"> <li>• AZT + 3TC + NVP or</li> <li>• AZT + 3TC + EFV</li> </ul> <p>Alternative recommended regimens:</p> <ul style="list-style-type: none"> <li>• TDF + 3TC (or FTC) + EFV and</li> <li>• TDF + 3TC (or FTC) +NVP</li> </ul>	<p><b>Option A (Maternal AZT)</b></p> <ul style="list-style-type: none"> <li>• AZT from 14th week</li> <li>• sd-NVP in labor *</li> <li>• AZT + 3TC in labor and delivery *</li> <li>• AZT +3TC 1 week post-partum*</li> </ul> <p>* Can be omitted if mother receives more than 4 weeks of AZT during pregnancy</p>	<p><b>Option B (Maternal Triple ARV prophylaxis)</b></p> <ul style="list-style-type: none"> <li>• A recommended course of triple ARVs from the 14th week of pregnancy until 1week after breastfeeding has finished</li> </ul> <p>The recommended maternal triple ARV regimens include AZT + 3TC + LPV/r; AZT + 3TC + ABC; AZT + 3TC + EFV; and TDF + 3TC (or FTC) + EFV.</p>

↓

**Infant: All infants, whose status is unknown or negative, will receive daily NVP or AZT for PMTCT. <sup>3</sup>**

If breastfeeding		If not breastfeeding	
Exclusively breastfeed for 6 months, then complementary feed and continue breastfeeding for the first 12 months of life. Not advised to rapidly wean.		The infant should have daily NVP or AZT for 6 weeks.	
<i>Infant drug regimens are linked to mother's course of medication.</i>			
<ul style="list-style-type: none"> <li>• If the mother is taking ARVs for her own health, the infant should have daily NVP for 6 weeks.</li> </ul>	<p><b>Option A</b></p> <ul style="list-style-type: none"> <li>• (Maternal AZT)</li> <li>• If the mother is taking AZT for the infant, then the infant should have daily NVP until 1 week after breastfeeding has finished.</li> </ul>	<p><b>Option B (Maternal Triple ARV prophylaxis)</b></p> <ul style="list-style-type: none"> <li>• If the mother is taking ARVs for her infant's health, then the infant should have daily NVP for 6 weeks.</li> </ul>	

<sup>3</sup> If infants are known to be HIV positive, mothers are encouraged to exclusively breastfeed for the first six months and continue breastfeeding, per the recommendations for the general population (up to 2 years) (Avert, 2011).

## ANNEX B. EFFECTS OF HIV-RELATED STIGMA AND DISCRIMINATION AT EACH STEP OF THE CASCADE

This table shows how stigma and discrimination affect each step of the PMTCT cascade. The table includes illustrative findings and references.

Effects of HIV-Related Stigma at Every Step of the PMTCT Cascade		
Step in the Cascade	How Stigma and Discrimination Affect the Cascade Step	Illustrative Findings and References
1. Initiating use of ANC	As routine opt-out HIV testing becomes standard and well-known in ANC clinics, women may avoid ANC services if they fear HIV testing and lack of confidentiality of HIV test results. While women have the right to opt out of HIV testing, the perception may be that they do not have a choice, or that if they refuse to test, ANC services will be compromised. In addition, women who are HIV positive or suspect that they are may fear S&D from healthcare workers during ANC.	<ul style="list-style-type: none"> <li>• In South Africa, HIV-positive mothers described delayed ANC attendance due to apprehension around HIV testing (Laher, Cescon et al. 2011)</li> <li>• In qualitative interviews in India and Vietnam, HIV-positive pregnant women described fears and experiences of S&amp;D from healthcare workers in ANC and maternity (Nguyen, Oosterhoff et al. 2008; Rahangdale, Banandur et al. 2010)</li> <li>• In Kenya, only 17 percent of ANC clients surveyed knew that HIV testing was optional (Ujiji, Rubenson et al. 2011)</li> </ul>
2. Being offered an HIV test	Beyond the health system barriers to offering an HIV test in ANC (lack of test kits, workers not trained, other system breakdowns), there is the potential for health workers' stigmatizing attitudes and stereotypes about who is at risk of HIV to affect who is offered HIV testing, resulting in some types of pregnant women not even being offered the test or others being tested without their consent. In addition, health workers may be uncomfortable offering testing in environments where HIV is stigmatized.	<ul style="list-style-type: none"> <li>• In Botswana, younger and more educated women and those residing in towns were more likely to be offered HIV counseling and testing than older, less educated, and rural women (Rakgoasi 2005).</li> <li>• In Vietnam, healthcare workers described offering HIV testing earlier in pregnancy to 'suspicious cases,' such as women who look like drug users or have certain jobs, such as 'hotel work' (Oosterhoff, Hardon et al. 2008).</li> <li>• In Kenya, maternity workers described testing pregnant women whom they suspected of being HIV positive without their knowledge or consent (Turan, Bukusi et al. 2008).</li> </ul>

Stigma and Discrimination: Key Barriers to Achieving Global Goals  
for Maternal Health and the Elimination of New Child HIV Infections

Effects of HIV-Related Stigma at Every Step of the PMTCT Cascade		
<p>3. Accepting an HIV test</p>	<p>Pregnant women may decline an HIV test for fear of being HIV positive, unwanted disclosure if found to be positive, and the S&amp;D that may follow. In some cases, women may face S&amp;D, including violence, from a male partner for just agreeing to an HIV test without his consent. Lack of trust in the confidentiality of test information, as well as the potential for unwanted disclosure of a positive status, may discourage a pregnant woman from accepting an HIV test.</p>	<ul style="list-style-type: none"> <li>• In Kenya, pregnant women who anticipated male partner stigma were more than two times more likely to refuse HIV testing during the ANC visit than other women, after adjusting for other factors (Turan, Bukusi et al. 2011).</li> <li>• In South Africa, health workers noted that fears of stigma often prevented pregnant woman from accepting HIV testing (Sprague, Chersich et al. 2011).</li> <li>• In Ethiopia, only 47 percent of pregnant women accepted HIV testing when offered, and qualitative interviews revealed the key role of fears of stigma in low testing uptake (Balcha, Lecerof et al. 2011).</li> </ul>
<p>4. Enrolling in PMTCT and/or HIV treatment services</p>	<p>Women may defer enrollment in these services at the time of HIV testing, often citing a need to go home and confer with their husband, and then never return to the health facility due to fears of HIV-related stigma. Women may also avoid enrollment in HIV care programs if they lack the support of their partner and live in a high-stigma setting. Although many ANC clinics provide women with all the ART drugs needed for both mother and infant for MTCT prophylaxis at the time of the initial HIV-positive test result (in case they never come back to the clinic), little is known about whether women are actually able to adhere to those medications.</p>	<ul style="list-style-type: none"> <li>• In a study in Nairobi, stigma was the most commonly cited barrier for HIV-positive pregnant women's failure to enroll in HIV care (77%)(Otieno, Kohler et al. 2010).</li> <li>• In rural Kenya, pregnant women with high levels of internalized HIV-related stigma were much less likely to enroll in HIV care after testing during ANC than those with low levels of internalized HIV-related stigma (Turan, Hatcher et al. Forthcoming (a)).</li> <li>• In Zimbabwe, stigma indicators were not significantly related to pregnant women's enrollment in HIV care, although the authors noted that more than two-thirds of the women were enrolled in psycho-social support groups that may have helped them cope with HIV-related stigma (Muchedzi, Chandisarewa et al. 2010).</li> </ul>
<p>5. Adhering to ART and follow-up visits during pregnancy</p>	<p>Even if women do enroll in PMTCT programs and/or HIV care, fears of unwanted disclosure, stigma, and discrimination may make it difficult for them to adhere to ART prophylaxis and/or HAART during pregnancy. Adherence becomes difficult if women need to hide HIV clinic visits and/or medications from others.</p>	<ul style="list-style-type: none"> <li>• In Kenya, both urban and rural women described the need to take measures to ensure that family and neighbors did not find out about their HIV-positive status during pregnancy and that this adversely affected their PMTCT adherence (Awiti Ujiji, Ekstrom et al. 2011).</li> <li>• In South Africa, pregnant women described having to hide their PMTCT medications from boyfriends, family members, and employers (Mephram, Zondi et al. 2011)</li> <li>• In another South African study, women who felt their HIV status was kept confidential at the health facility were significantly more likely to report adherence to single-dose nevirapine during pregnancy (Peltzer, Mlambo et al. 2010).</li> </ul>

Effects of HIV-Related Stigma at Every Step of the PMTCT Cascade		
6. Giving birth with a skilled attendant	Fears about lack of confidentiality, unwanted disclosure, and HIV-related stigma may cause some women to avoid childbirth in a health facility. Crowded labor and delivery wards present multiple opportunities for unwanted disclosure of HIV status, as well as stigma and discrimination from healthcare providers.	<ul style="list-style-type: none"> <li>• In urban Kenya, fears of unwanted disclosure and stigma from neighbors contributed to HIV-positive women's decisions to give birth at home (Awiti Ujji, Ekstrom et al. 2011).</li> <li>• In rural Kenya, pregnant women who held stigmatizing and discriminatory views about PLHIV were less likely to deliver in a health facility, even after controlling for a variety of factors known to be associated with facility-based delivery (Turan, Hatcher et al. Forthcoming (b)).</li> <li>• In rural Kenya, HIV-positive women who had disclosed their HIV status to anyone were 6.5 times more likely to deliver in a health facility than HIV-positive women who had not disclosed to anyone, even after controlling for other factors associated with childbirth in a health facility (Turan, Onono et al. 2011).</li> </ul>
7. Adhering to recommended infant feeding practices	Women may fear that following an infant feeding regime that is not the cultural norm/standard (e.g., exclusive breastfeeding or formula feeding) will lead to disclosure of HIV status. As recommended infant feeding practices for positive mothers become more widely known, exclusive breastfeeding may become a marker for HIV infection.	<ul style="list-style-type: none"> <li>• In Burkina Faso, Cambodia, and Cameroon, HIV-positive women made infant feeding decisions based on their perceptions of the risk of being stigmatized as a "bad mother" or as HIV positive (Desclaux and Alfieri 2009).</li> <li>• In Kenya, HIV-positive women who did not stop breastfeeding at 6 months as recommended were most concerned about stigma (Morgan, Masaba et al. 2010).</li> <li>• In Kenya, HIV-positive women who had already disclosed their HIV status were significantly more likely to be practicing exclusive breastfeeding at 4–8 weeks after the birth than other women (Onono, Bukusi et al. 2011).</li> </ul>
8. Bringing infant in for HIV testing	Similar factors related to HIV-related stigma have been shown to come into play in parents' utilization of infant HIV testing services. Stigma directed toward adult caregivers may translate into delays in seeking testing and care for infants.	<ul style="list-style-type: none"> <li>• In South Africa, although HIV-related stigma and discrimination scores were not significantly associated with the uptake of infant testing, women who had shared their HIV test result with someone were 2.5 times more likely to have had their infant tested for HIV than those who had not shared with anyone (Peltzer and Mlambo 2010).</li> <li>• In Mozambique, researchers attributed the association between HIV-positive women's greater distance from the hospital and uptake of early infant diagnosis services to the decreased stigma associated with seeking HIV care outside of one's own community (Cook, Ciampa et al. 2011).</li> <li>• A study in Kenya found that health systems factors were more important than selected measures of HIV-related stigma in explaining infant testing uptake (Kinuthia, Kiarie et al. 2011).</li> </ul>

Stigma and Discrimination: Key Barriers to Achieving Global Goals  
for Maternal Health and the Elimination of New Child HIV Infections

Effects of HIV-Related Stigma at Every Step of the PMTCT Cascade		
9. Adhering to maternal and infant follow-up visits and ART after the birth	After the birth, fears of stigma and discrimination can again be barriers to adherence to ART for infant and/or self, due to the need to hide visits and/or medications from others. This step gains great importance in the face of the latest recommendations for continuing ART for mothers and infants throughout breastfeeding and longer.	<ul style="list-style-type: none"> <li>• In South Africa, women who had disclosed their HIV-positive status to their partner were significantly more likely to adhere to infant nevirapine (Peltzer, Mlambo et al. 2010).</li> <li>• In Rwanda, infants of women who had not disclosed their HIV status to someone other than a partner were less likely to have received infant nevirapine at the recommended time (Delvaux, Elul et al. 2009).</li> </ul>

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