Stigma and discrimination as barriers to achievement of global PMTCT and maternal health goals

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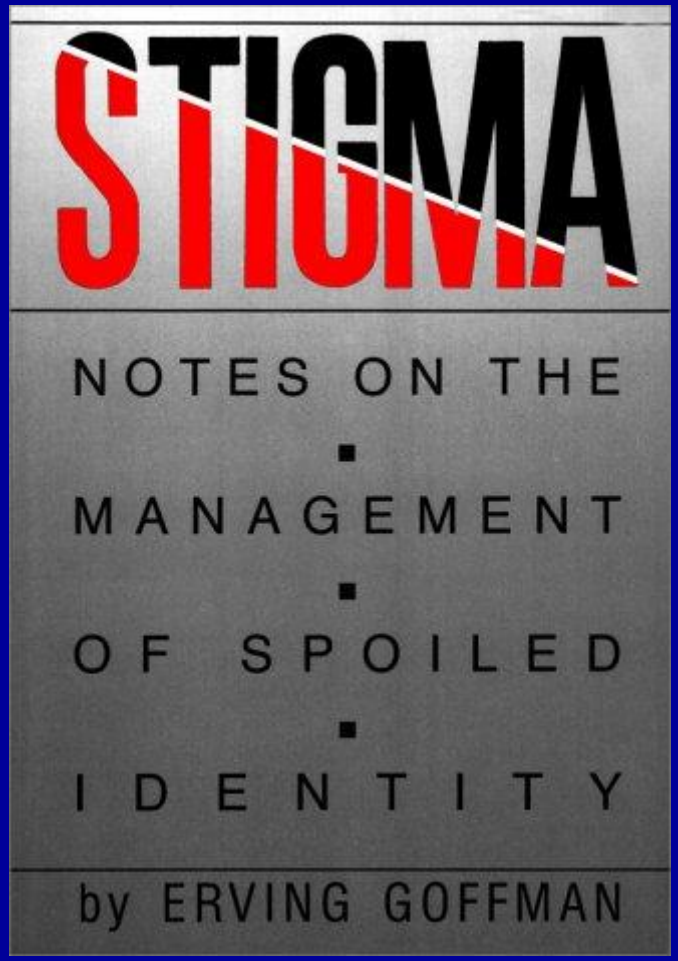
Possible pathways for the effects of HIV on maternal health:

1. Increases in susceptibility to:
   - HIV-related infections, including TB and malaria
   - Advancing HIV disease
   - Pregnancy & birth complications
2. Adverse effects of HIV-related stigma and discrimination on utilization and quality of maternity services
   - For all women
   - For women living with HIV

What is Stigma?



- A social process in which individuals with certain attributes or behaviors *lose social value*

- Examples of stigmatized health conditions:
  - HIV and AIDS
  - Tuberculosis
  - Obesity
  - Mental illness
  - Substance abuse disorders

Dimensions of stigma

- Anticipated stigma (fears)
- Perceptions of community norms
- Experienced, enacted or observed stigma (discrimination)
- Internalized or self stigma

Special Vulnerability of HIV-Positive Pregnant and Childbearing Women

- Often 1st person in the family to be tested for HIV → blame
- Gender norms/relations that penalize women for promiscuity → blame
- Negative judgments about HIV-positive women having babies → blame
- Issue of risk to the unborn/newborn child
- Different infant feeding practices can cause unwanted disclosure
- Socio-economic vulnerability

The New York Times

Health

GLOBAL UPDATE

Stigma of H.I.V. Is a Barrier to Prenatal Care

Rachel Steinfeld

By DONALD G. McNEIL Jr.
Published: August 27, 2012

Strategic Review*

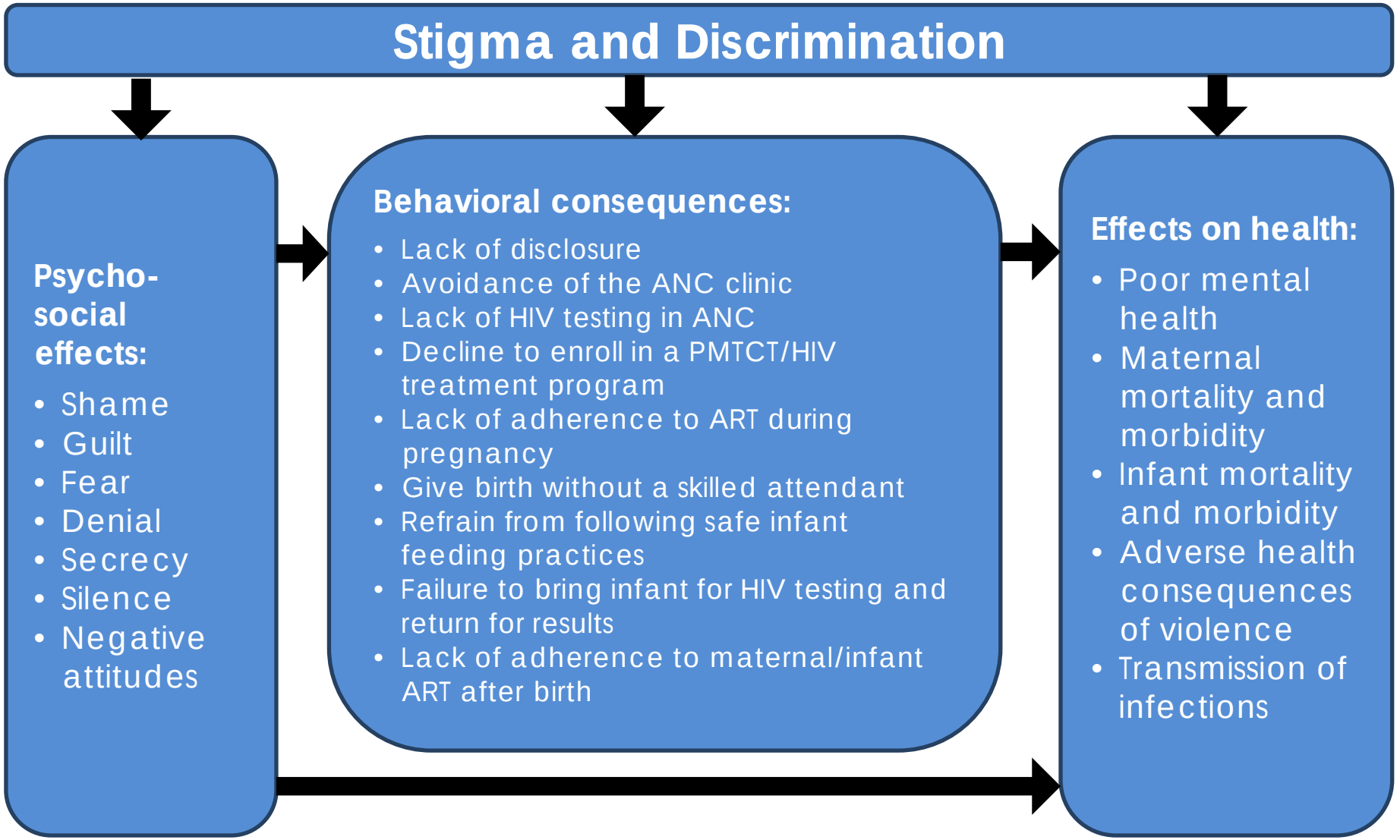
STIGMA AND DISCRIMINATION: KEY BARRIERS TO ACHIEVING GLOBAL GOALS FOR MATERNAL HEALTH AND ELIMINATION OF NEW CHILD HIV INFECTIONS

A review of the existing academic and programmatic literature on how stigma and discrimination affect each step in the PMTCT cascade

* HPP working paper: http://www.healthpolicyproject.com/pubs/92_WorkingPaperStigmaPMTCTJuly.pdf

* Turan and Nyblade, AIDS & Behavior, 2013

A Framework for the Effects of Stigma on Maternal, Neonatal, and Child Health



Examples of HIV-Related Stigma Experienced by Pregnant Women

- **Anticipated stigma:**
  - A focus group 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:**
  - In a study of participants in a PMTCT program in Malawi, half had dropped out of the program, citing reasons including "involuntary HIV disclosure and negative community reactions"

  (Chinkonde, Sundby et al. 2009)

Examples of HIV-related Stigma Experienced by Pregnant Women

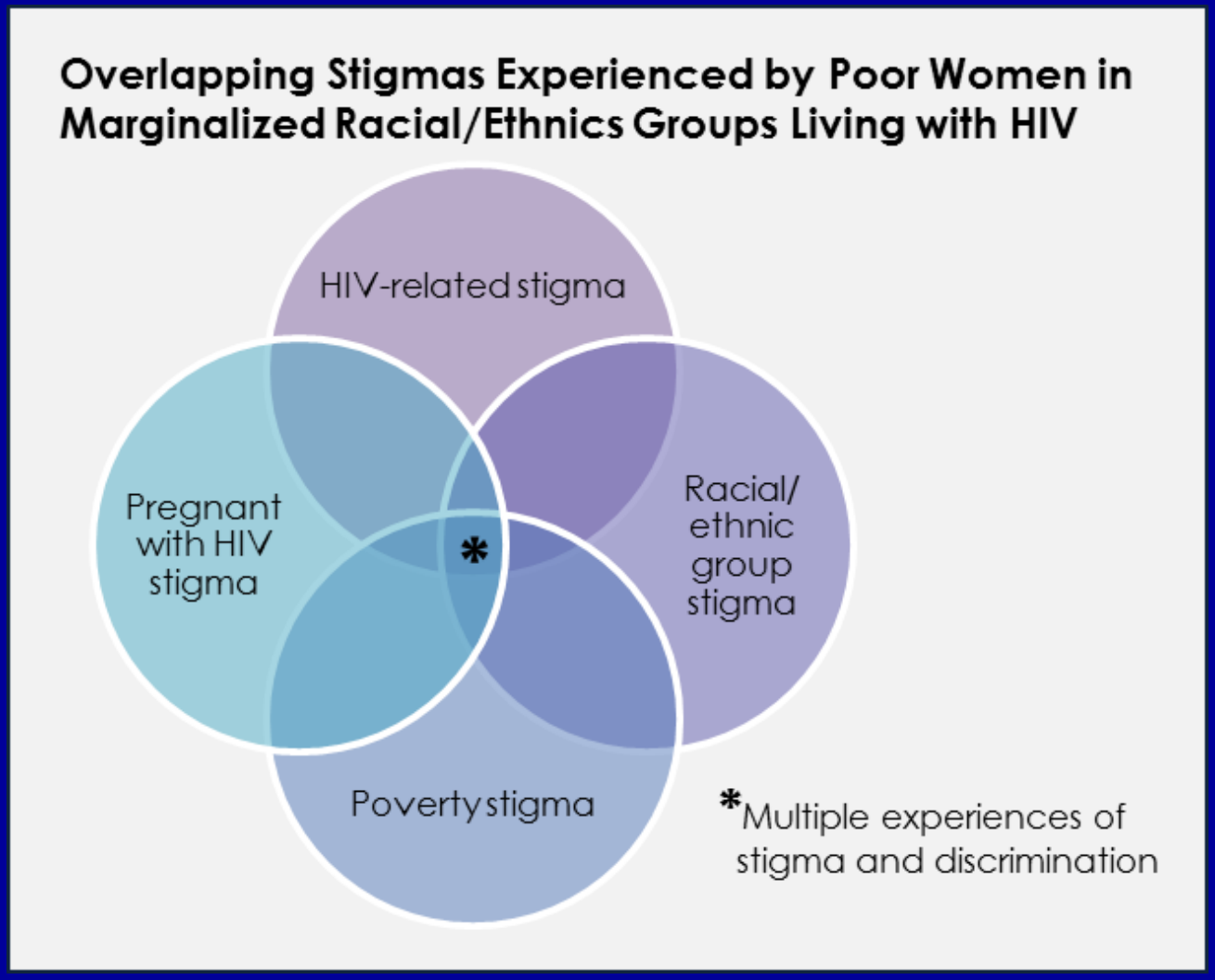
- **Self-stigma:**
  - HIV-positive women participating in focus groups in India judged themselves negatively for not being able to be good mothers and properly care for their own children due to their HIV infection.

    (Rahangdale, Banandur et al. 2010)

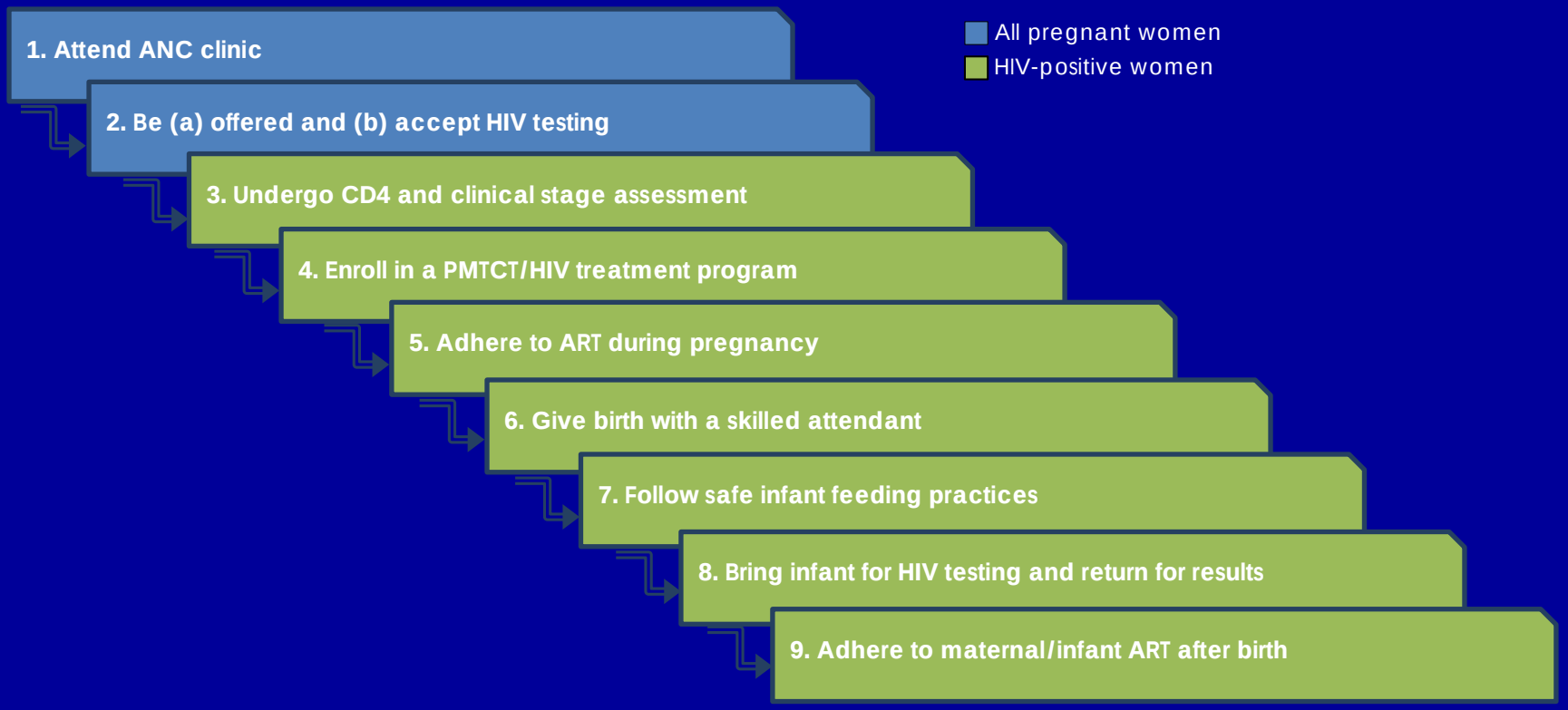
- **Enacted stigma:**
  - In Mexico, a young woman related the following experience: "The doctor said: 'How can you even think about getting pregnant knowing that you will kill your child because you're positive?!!!' He threatened not to see me again if I got pregnant. He told me that I was 'irresponsible,'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

    (Kendall 2009)

Overlapping Stigmas



Stigma and discrimination affect each step in the PMTCT cascade



Overall Review Findings

- A wealth of qualitative data, and some quantitative data, on effects of stigma on PMTCT and maternal health
- Negative effects 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
- Effects on maternal health and new infant HIV infections are likely to be cumulative and substantial

Conclusions

- Unlikely that the global commitments to virtual elimination of new HIV infections in children and reduced HIV- related maternal mortality by 2015 will be met unless major efforts are made to identify and counter HIV-related stigma facing pregnant women*
- Existing stigma-reduction tools and interventions, as well as measures to evaluate progress, can be modified for the specific needs of pregnant women
- *While it has yet to be fully recognized, reducing stigma is an essential piece of delivering care for all women, men, and children*

* Turan and Nyblade, JAIDS, 2013

The MAMAS Study

Maternity in Migori and AIDS Stigma Study

(PI: Janet M. Turan)

Investigating the relationships between women's perceptions and experiences of HIV-related stigma and their use of essential maternity and HIV services in rural Kenya

UCSF University of California San Francisco

UAB SCHOOL OF PUBLIC HEALTH

KENYA MEDICAL RESEARCH INSTITUTE KEMRI

Funded by the U.S. National Institute of Mental Health (NIMH)

MAMAS Results on Refusal of HIV testing during Pregnancy*

- Pregnant women who anticipated male partner stigma were more than twice as likely to refuse HIV testing, after adjusting for other individual-level predictors
  - Odds Ratio=2.10, 95% CI: 1.15-3.85, p=.016

- Other variables in the model:
  - Anticipated stigma from other family members (ns)
  - Anticipated stigma from other people (ns)
  - Total perceived community stigma score (ns)
  - Knowing someone with HIV (OR =.52)
  - Lack of knowledge of male partner's HIV testing status (OR=1.77)

* Turan et al., AIDS & Behavior, 2011

Use of Essential Maternity Services

- Fears about lack of confidentiality, unwanted disclosure, and HIV-related stigma may cause some women to avoid ANC clinics and childbirth in a health facility.

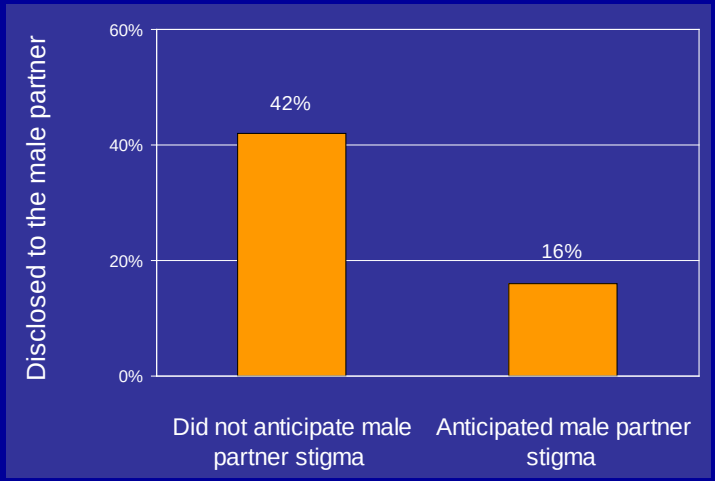
- Illustrative finding from MAMAS:
  - In rural Kenya, women with higher perceptions of HIV-related stigma at baseline were subsequently less likely to deliver in a health facility with a skilled attendant, even after adjusting for other known predictors of health facility delivery (AOR=0.44, 95% CI:0.22-0.88).

Turan et al., PLoS Medicine, 2012

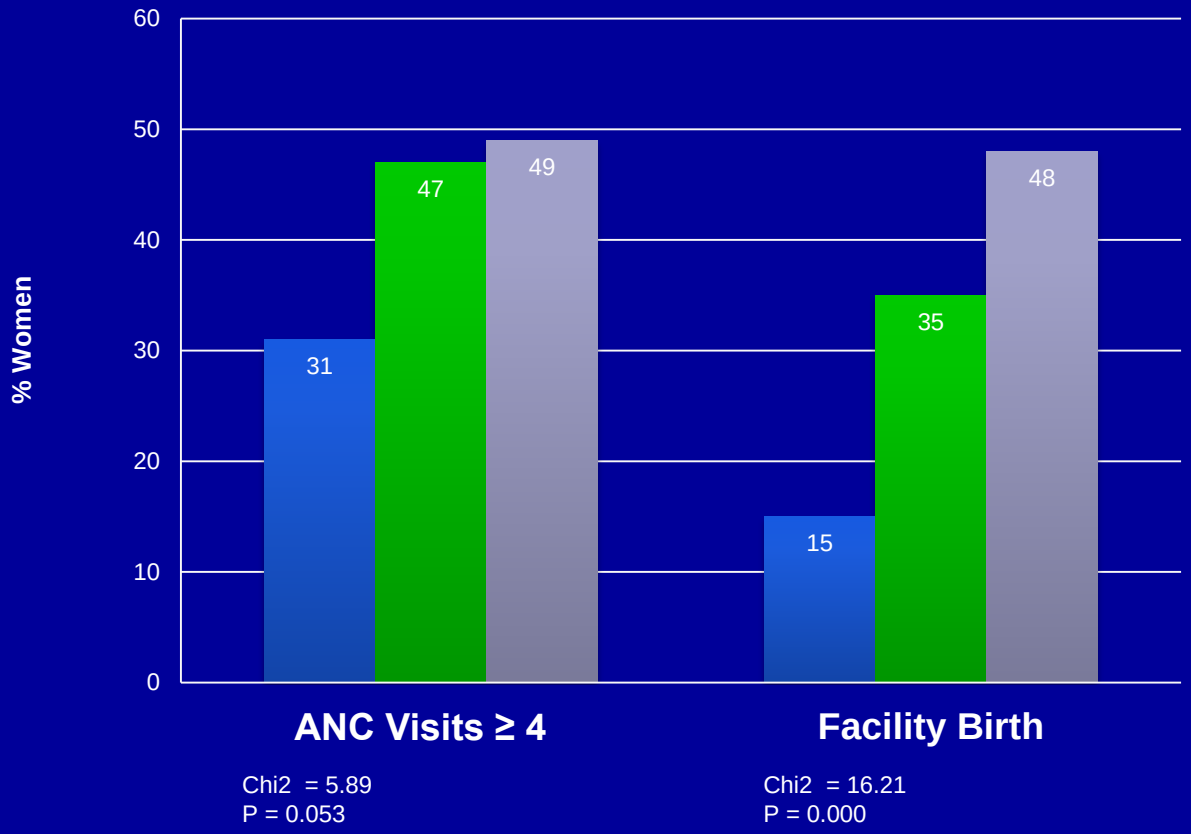
Lack of Disclosure

- A behavioral consequence of stigma and potentially a key pathway for the effects of stigma on health

- For HIV-positive women in MAMAS (n=156):
  - Only 58% had disclosed their HIV status to *anyone* by 6 weeks after the birth
  - Only 31% had disclosed to their male partner



Disclosure and Use of ANC and Facility Birth Services



- HIV-pos undisclosed (n=59)
- HIV-neg or unknown (n=245)
- HIV-pos disclosed (n=86)

* Spangler et al., manuscript in preparation

What can we do?*

- Address and mitigate these social factors which contribute to poor maternal health outcomes and are barriers to treatment and care

- Promote social support for pregnant and postpartum women and mobilize communities in favor of respectful, high-quality HIV and MCH services

- Improve the evidence base:
  - Evaluate the effects of stigma-reduction and related interventions on maternal outcomes
  - Test interventions that aim to transform the social environment to support women's use of HIV and MCH services

* Adapted from MHTF Maternal Health and HIV Policy Brief, December 2013

Planned Intervention Studies in rural Kenya

- Home-based couples intervention to increase couple HIV counseling and testing (CHCT), safe disclosure, and family health
- Test of interventions to help pregnant women living with HIV with medication adherence and retention in HIV care
  - Community-based Mentor Mothers
  - Text messaging

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