

# 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

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GLOBAL UPDATE

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

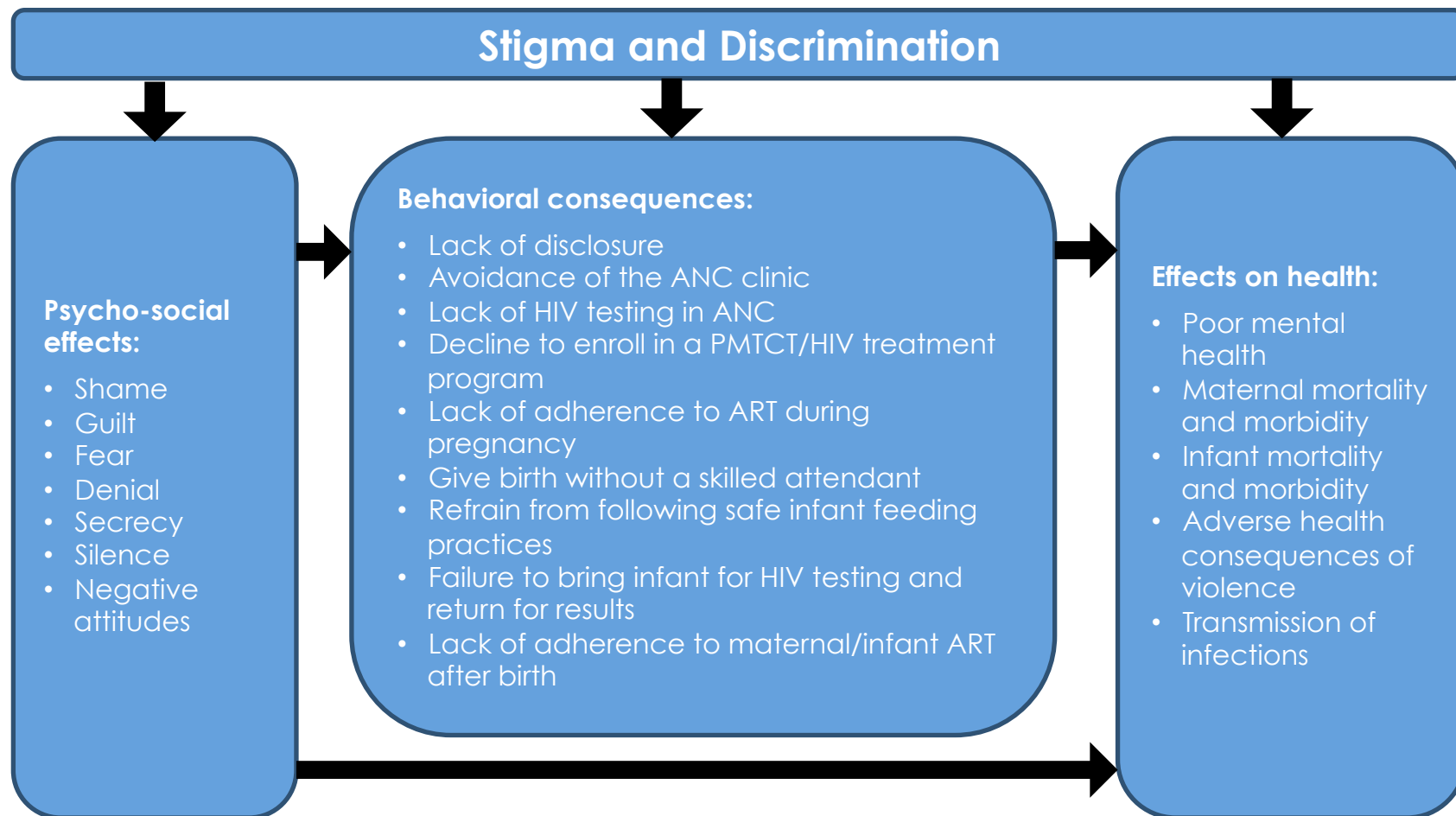


Rachel Steinfeld

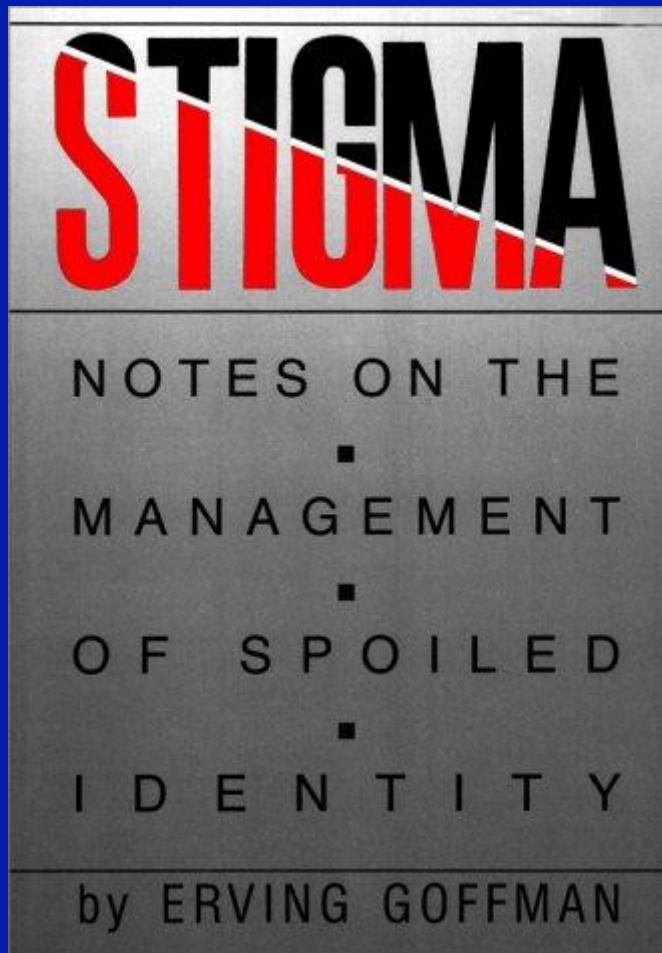
By [DONALD G. McNEIL Jr.](#)

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



# What is Stigma?



- A social process in which individuals with certain attributes or behaviors *lose social value*
- Examples of stigmatized health conditions:
  - HIV/AIDS
  - Tuberculosis
  - Obesity
  - Mental illness
  - Substance abuse disorders

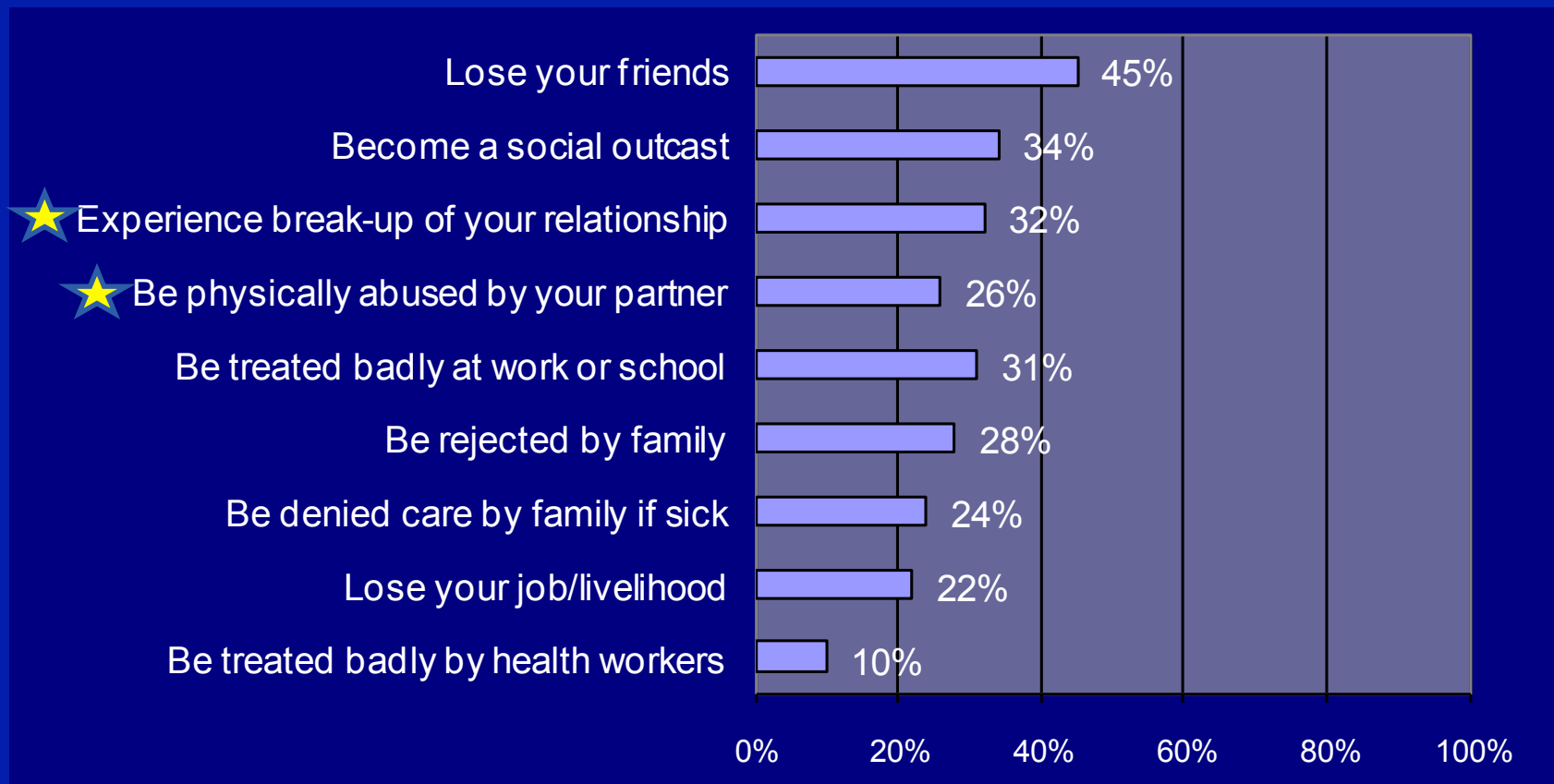
# Dimensions of stigma

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

# Special Vulnerability of HIV-Positive Pregnant and Childbearing Women

- Often 1<sup>st</sup> 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

# Rates of anticipated HIV-related stigma among pregnant women are high\*



\* Turan et al., AIDS & Behav, 2011.



# 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)

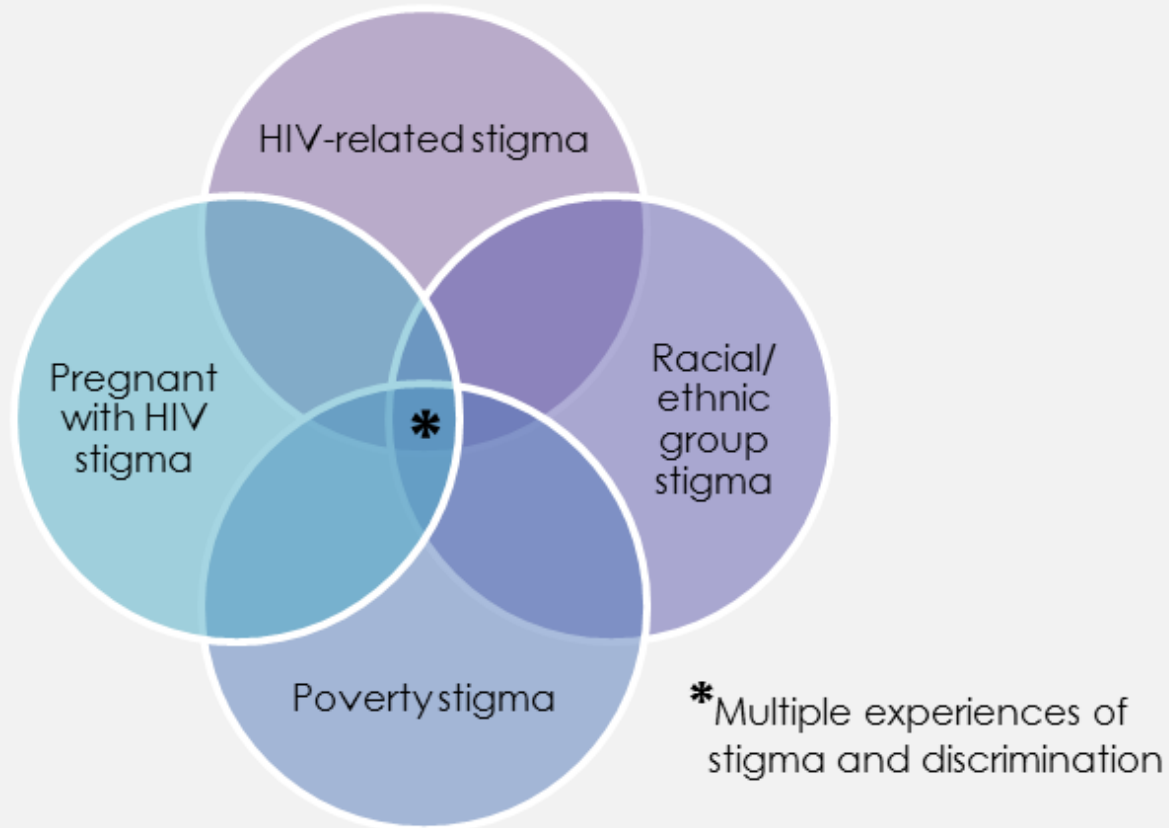
- **Enacted stigma:**

- 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)

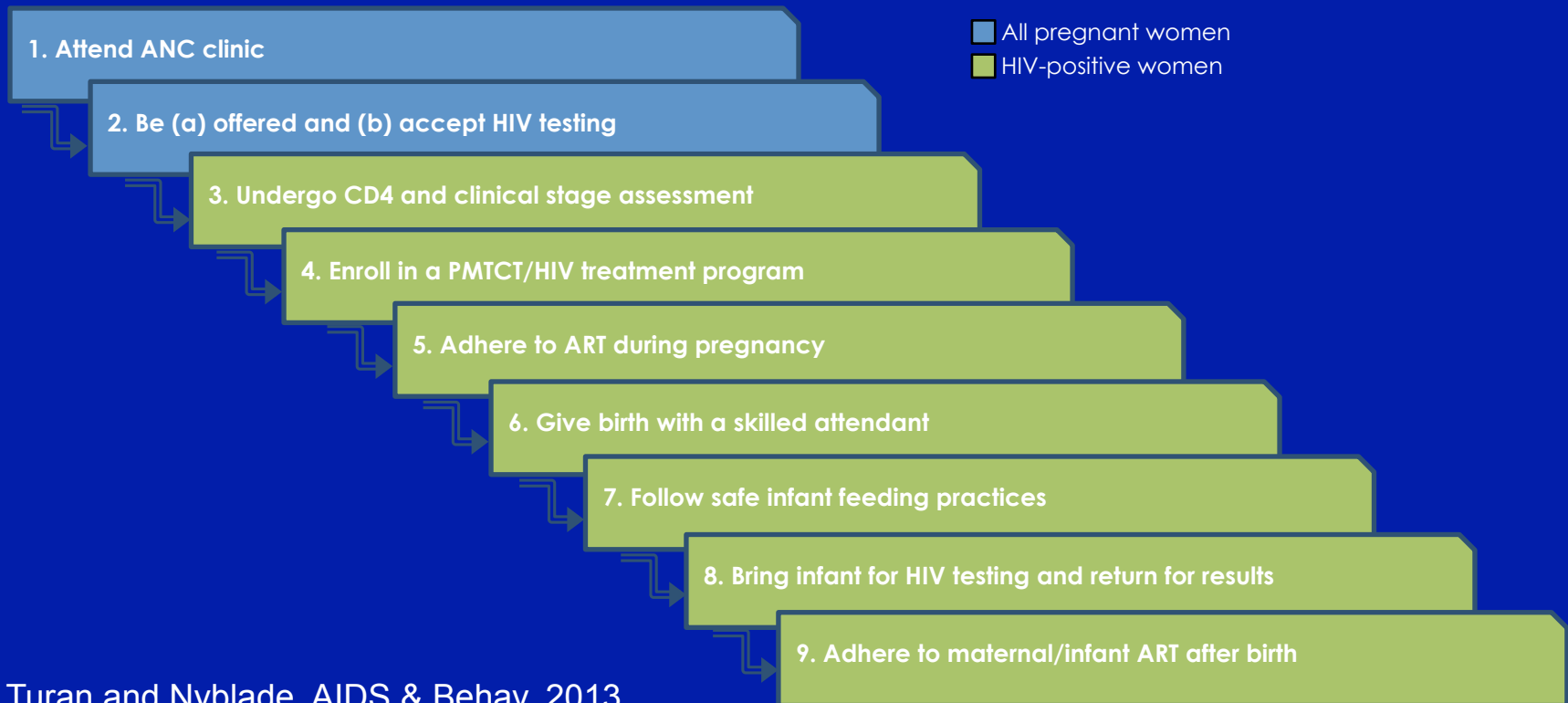
# Overlapping Stigmas

**Overlapping Stigmas Experienced by Poor Women in Marginalized Racial/Ethnic Groups Living with HIV**



# Strategic Review\*

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

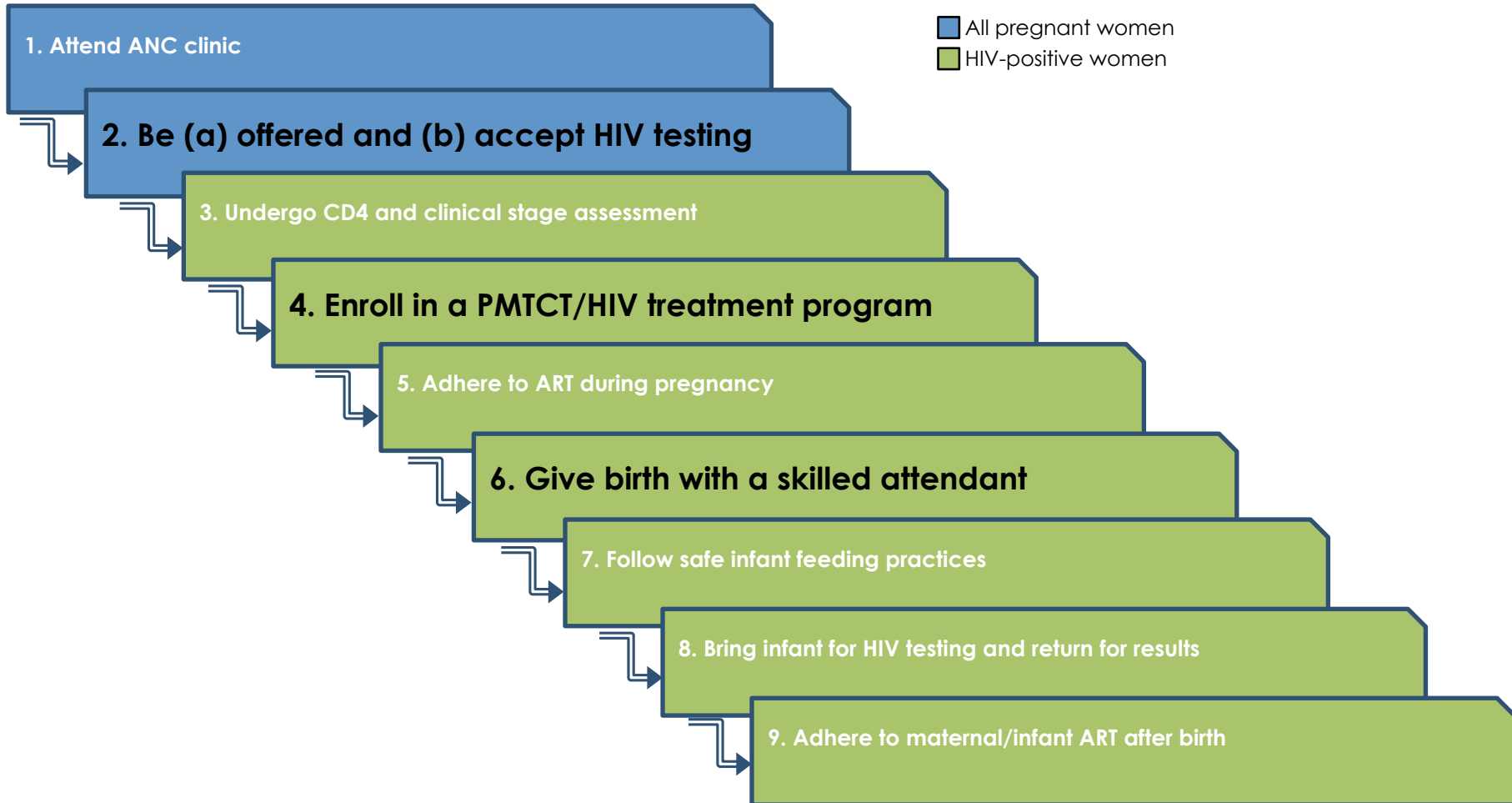


\* Turan and Nyblade, AIDS & Behav, 2013

\*HPP working paper: [http://www.healthpolicyproject.com/pubs/92\\_WorkingPaperStigmaPMTCTJuly.pdf](http://www.healthpolicyproject.com/pubs/92_WorkingPaperStigmaPMTCTJuly.pdf)

# Overall Review Findings

- A wealth of qualitative data, and some quantitative data, on effects of stigma on PMTCT
- 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



# 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



University of California  
San Francisco

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



# HIV Testing during ANC

- Pregnant women may decline an HIV test for fear of being HIV-positive, unwanted disclosure if found to be positive, and the S&D that may follow.
- Illustrative finding:
  - 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](#))



# MAMAS Results\*

- 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 & Behav, 2011.

# Enrollment in PMTCT and/or HIV Treatment Programs

- 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.
- Illustrative finding:
  - 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 et al., 2010)

# MAMAS Results: A Multivariate Model for Factors Associated with Enrollment in HIV Care (adjusted analysis)\*

Variable	OR for linkage to care (p value)
Husband has other wives	0.83 (.631)
Works in farming vs. other occupations	1.72 (.022)
Time in minutes from home to HF (continuous)	1.008 (.025)
Four or more ANC visits during pregnancy	2.38 (.013)
<b><i>Self stigma (continuous score)</i></b>	<b>0.56 (.013)</b>
Depression (EPDS $\geq$ 13)	0.85 (.631)
Family knows about HIV+ status	1.59 (.341)

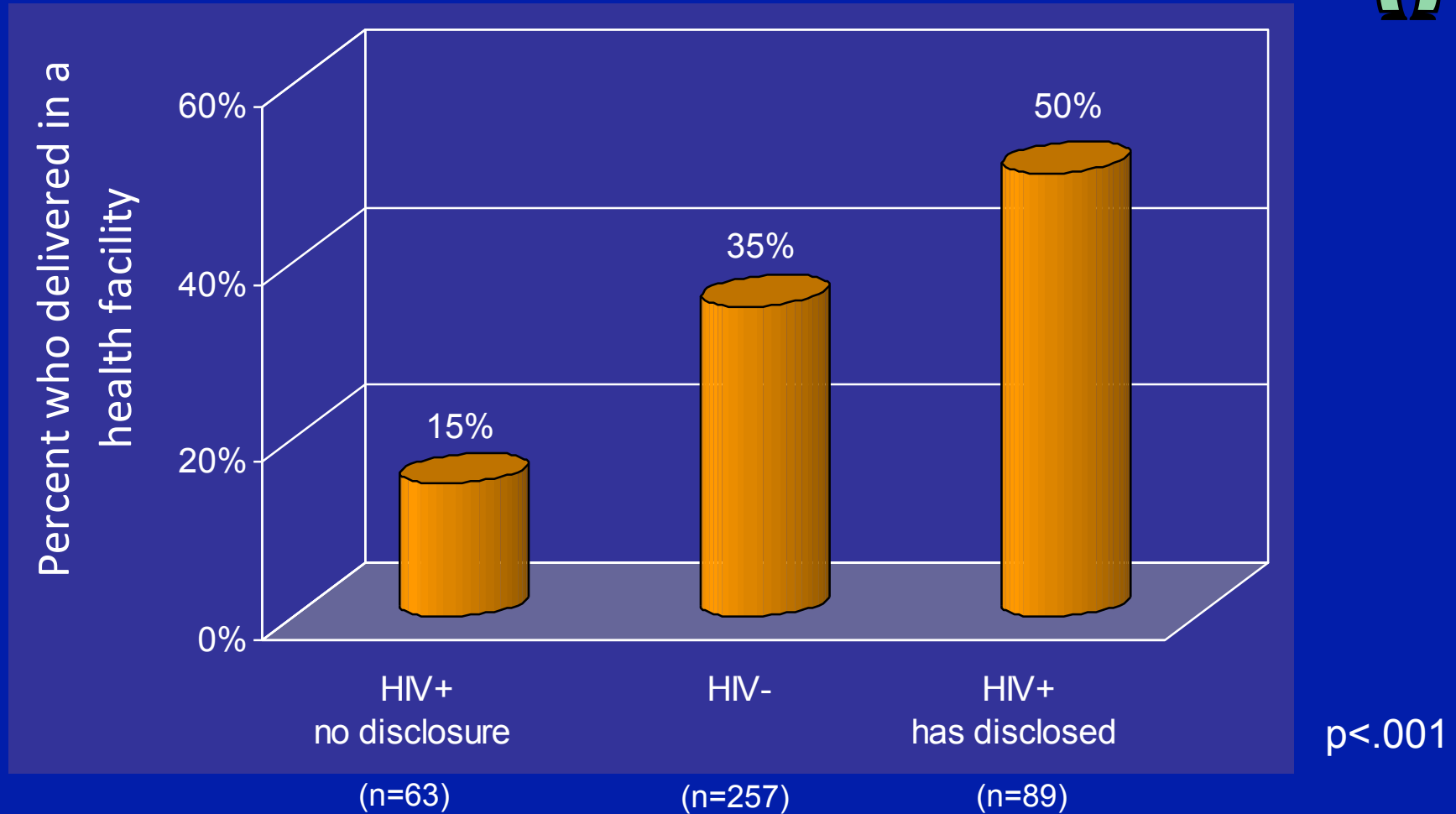
\* Obtained using multivariate logistic regression, accounting for clustering by site using robust standard errors

# 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.
- Illustrative finding:
  - 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)

# Effects of Disclosure on Use of Skilled Delivery Services\*



\* Turan et al., manuscript in preparation

# 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, forthcoming

# Acknowledgements:

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