

# HIV-related Stigma in Health Care Settings

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# Learning Objectives

- Overview of HIV in the United States
- Introduction to Stigma
- HIV-Related Stigma
- Addressing Stigma and Discrimination

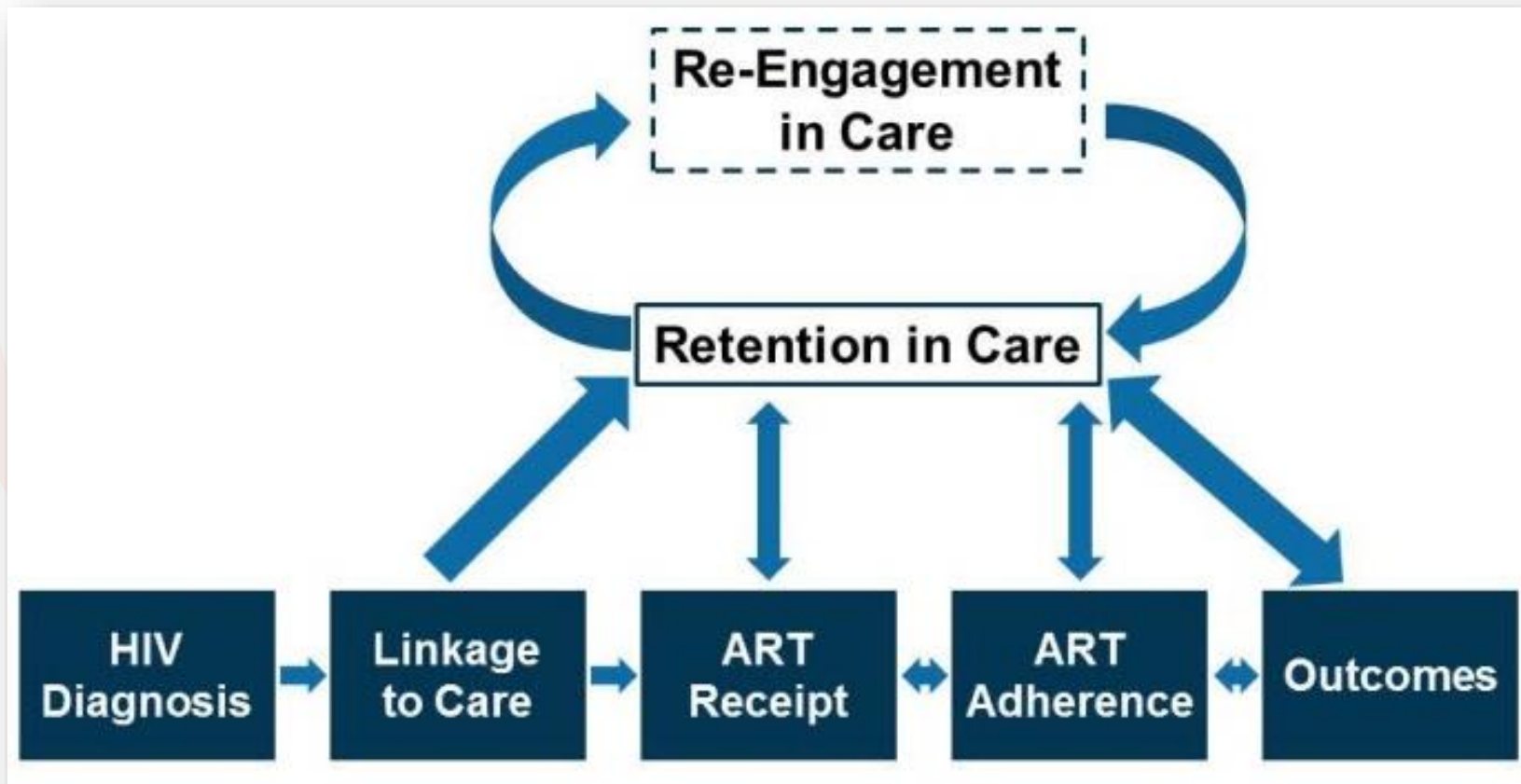


# Audience Poll

I believe there are measurable ways to decrease HIV-related stigma in health care settings?

- Yes
- No

# Steps to Achieve Optimal Outcomes



# National HIV/AIDS Strategy

- There is still an HIV epidemic and it remains a major health issue for the United States.
- Most people can live long, healthy lives with HIV if they are diagnosed and get treatment.
- For a variety of reasons, certain populations bear a disproportionate burden of HIV.
- People across the nation deserve access to tools and education to prevent HIV transmission.
- Every person diagnosed with HIV deserves immediate access to treatment and care that is **non-stigmatizing**, competent, and responsive to the needs of the diverse populations impacted by HIV

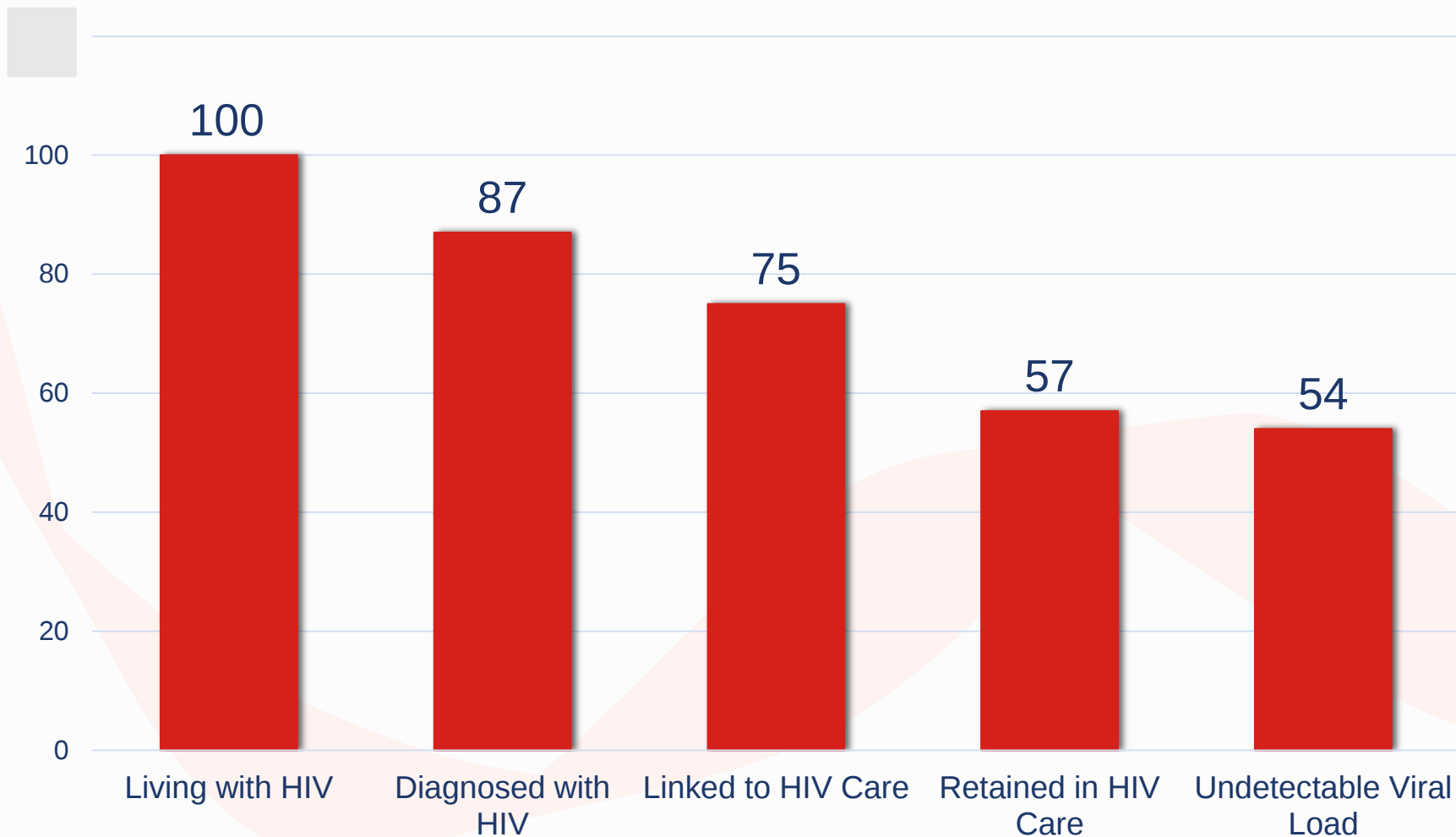
# National HIV/AIDS Strategy

- Stigma and discrimination must be eliminated in order to diminish barriers to HIV prevention, testing, and care.
- HIV-related stigma can be confounded by or complicated with stigma related to substance use, mental health, sexual orientation, gender identity, race/ethnicity, or sex work.
- Stigma can lead to many negative consequences for people living with HIV.

# Stigma as a Barrier to Care and Engagement

- Fear of HIV testing
- Avoidance of facilities for HIV and other health-related services
- Non-disclosure of important health information
- Travel outside of community to access medications and treatment
- May not access needed HIV prevention services or information
- Avoidance of disclosure to sexual partners

# United States HIV Care Continuum



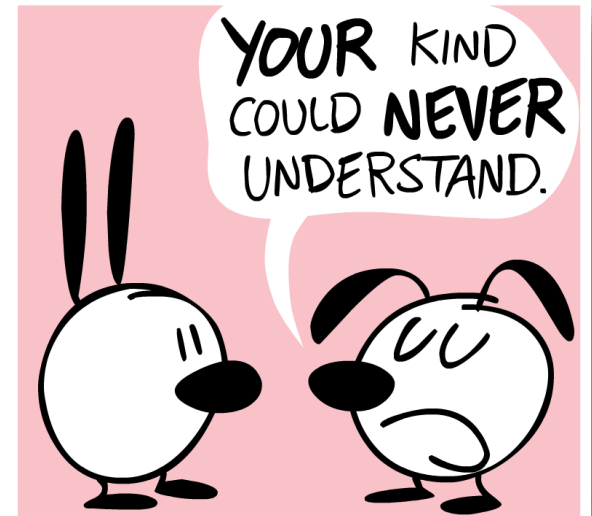
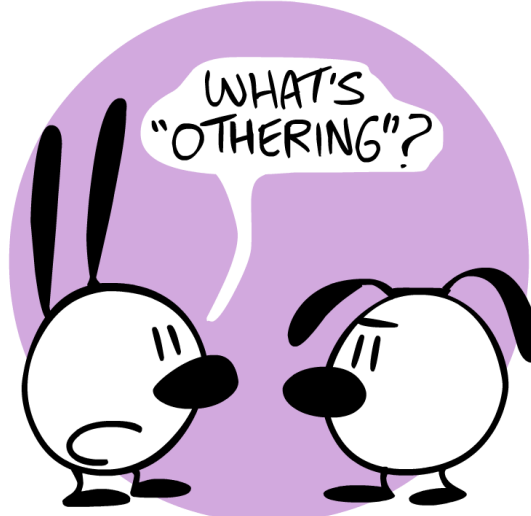


# INTRODUCTION TO STIGMA

# Othering



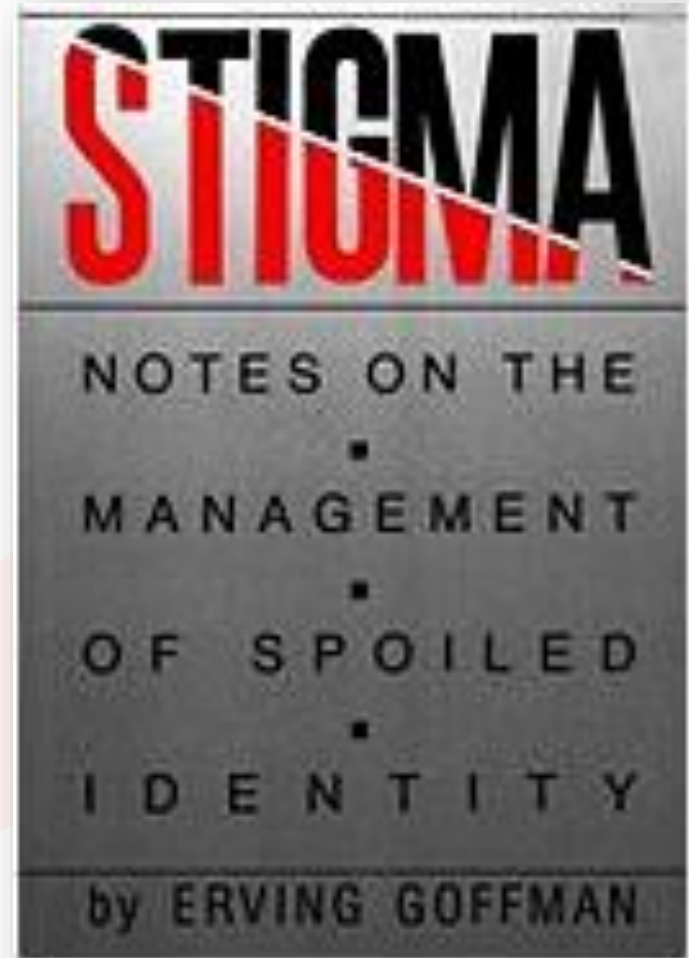
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# STIGMA:

## Notes on the Management of Spoiled Identity

- Erving Goffman, Sociologist who wrote about
  - Types of stigma
  - How individuals deal with stigma
  - How persons with stigma relate to others



# Stigma

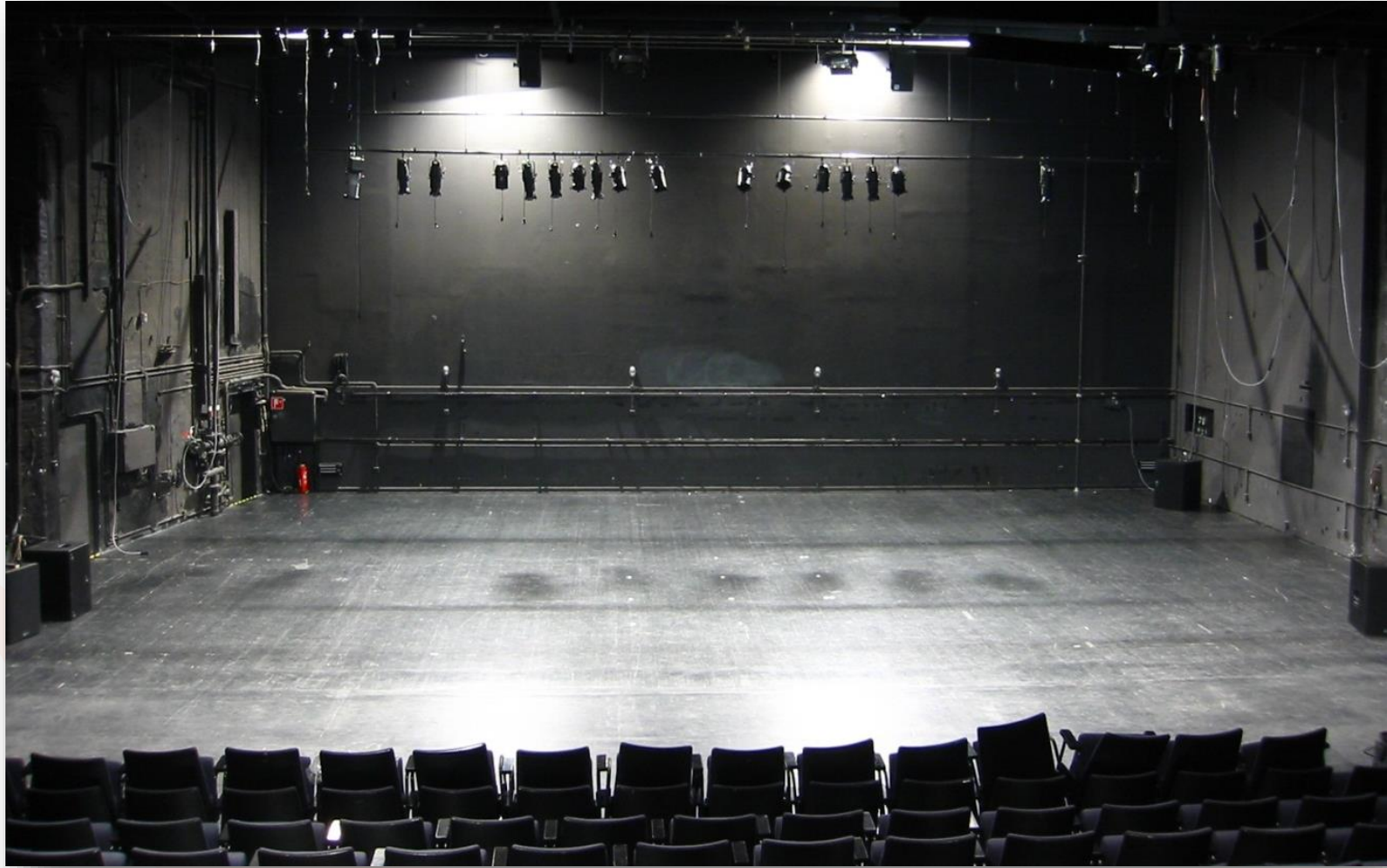
“[Stigma is] an attribute that links a person to an undesirable stereotype, leading other people to reduce the bearer from a whole and usual person to a tainted, discounted one.”

# Types of Stigma

- Discredited Stigma
- Discreditable Stigma



# The Stage Theory



# Goffman's Theatre

- Backstage
  - The “Own”
  - The “Wise”
- Audience
  - The “Normals”



# Goffman's Coping Mechanisms

Some stigmatized people can physically remove their stigma

People can master those areas that stigmatize them

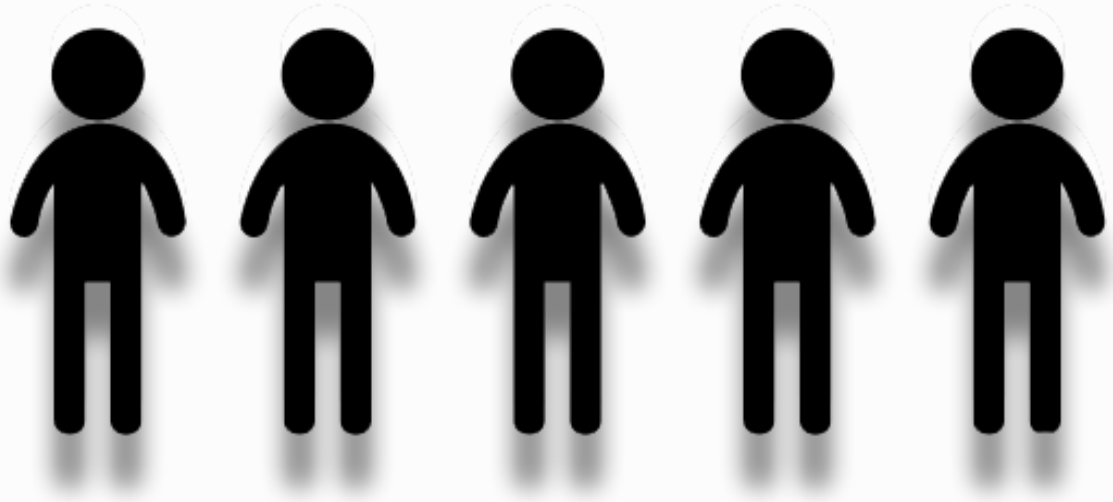
Stigmatized people can use their stigma for secondary gain

Stigmatized persons can come to view their stigma as a blessing

A stigma can cause people to reassess the limits of normals

Stigmatized persons can avoid contact with normals

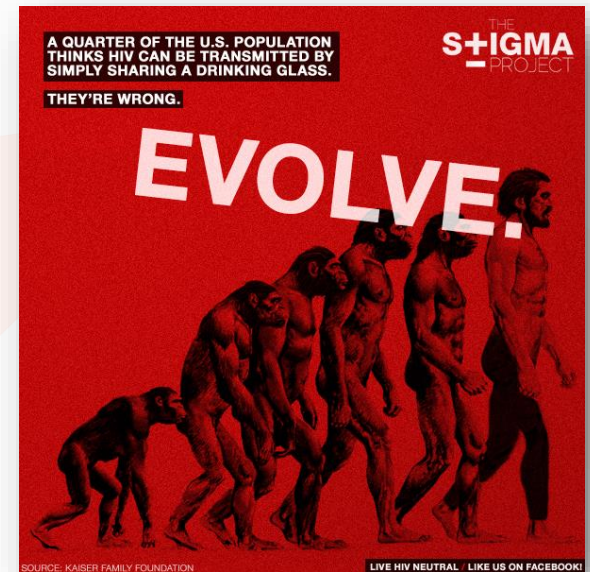
Stigmatized people seek out sympathetic others



# HIV-RELATED STIGMA AND DISCRIMINATION

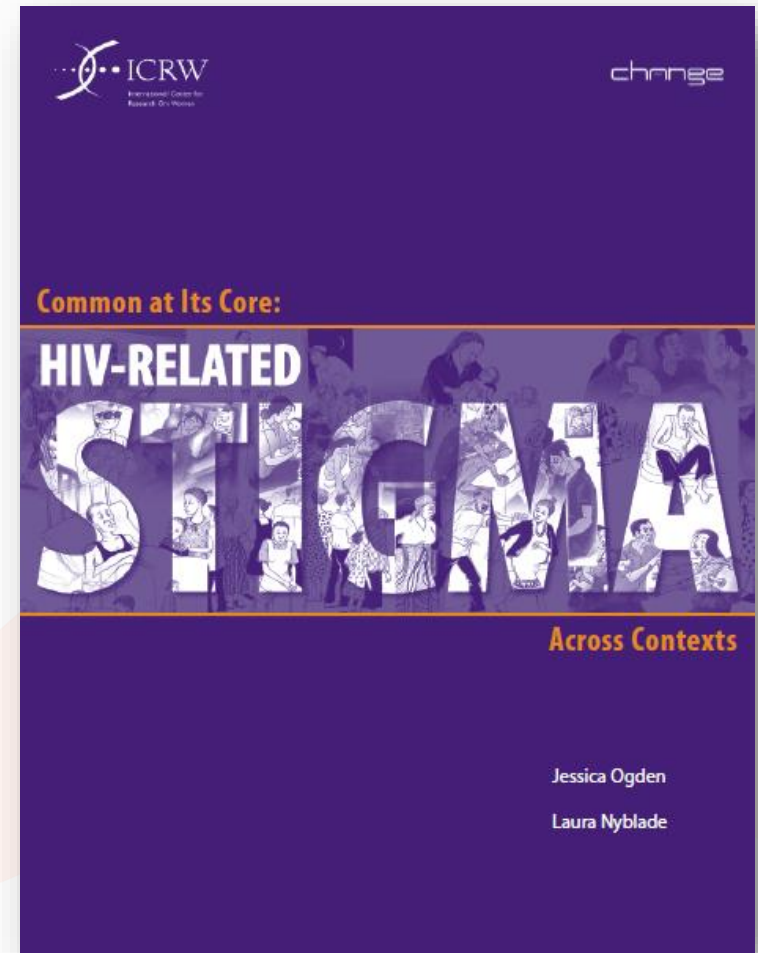
# HIV-related Stigma

HIV/AIDS-related stigma is a complex concept that refers to prejudice, discounting, discrediting and discrimination directed at persons perceived to have AIDS or HIV, as well as their partners, friends, families and communities.



# Common at its Core

- Published in 2005
- Authors Jessica Ogden, Laura Nyblade
- Synthesis report of several different researchers
- Identifies commonalities in HIV-related stigma globally



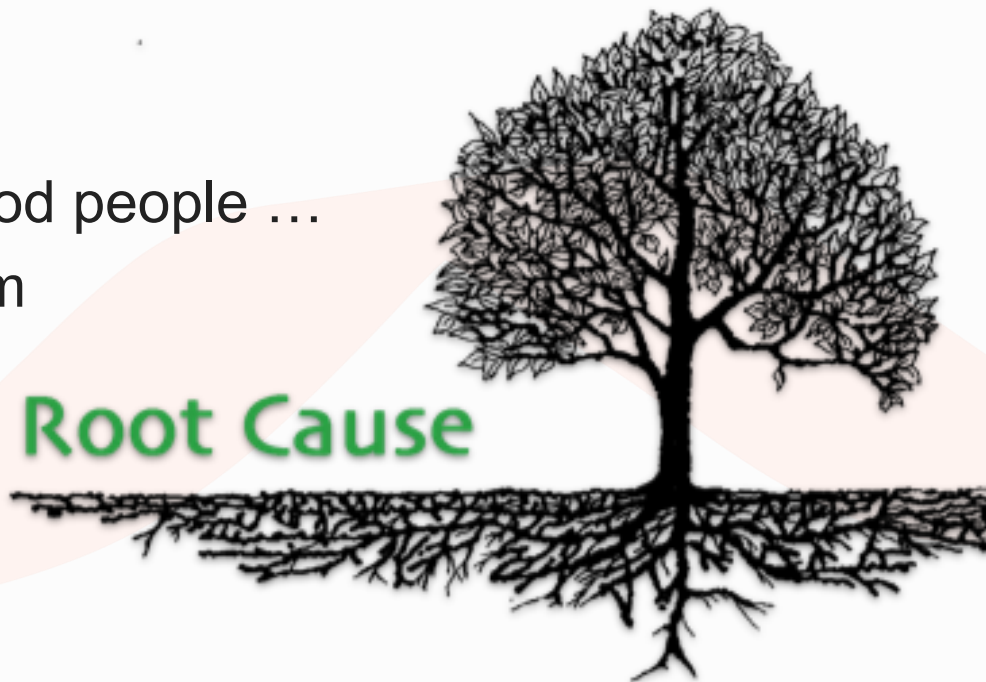
# Common at its Core

- “... evidence suggests that HIV and AIDS-related stigma is far less varied and context specific than many have been imagined.”
- “HIV and AIDS have all the characteristics associated with heavily stigmatized medical conditions.”



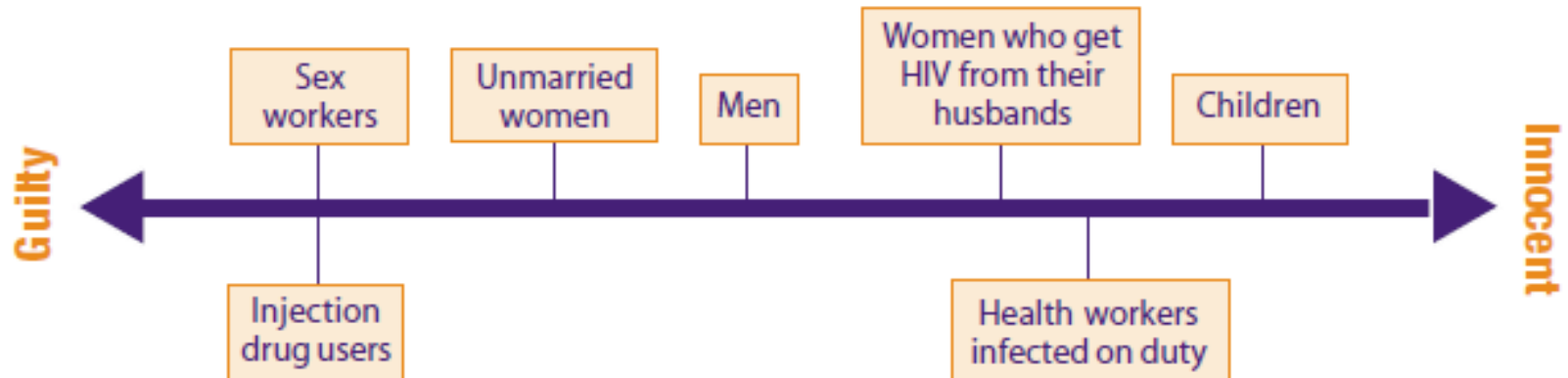
# Root Causes of Stigma

- Knowledge
  - Lack of knowledge leads to fear
  - Fear-based messaging complicates prevention and care
- Morality
  - The “karma” effect
  - Good things happen to good people ...
  - Innocence-Guilt Continuum



# Innocence to Guilt Continuum

**Box 3: Schematic of “Innocence-to-Guilt” Continuum**



# How do people stigmatize?

- Isolation and Rejection
- Shaming and Blaming
- Discrimination (Enacted Stigma)
- Self-Stigma
- Stigma by Association
- Layered Stigma



# Forms of Stigma in Health Facilities

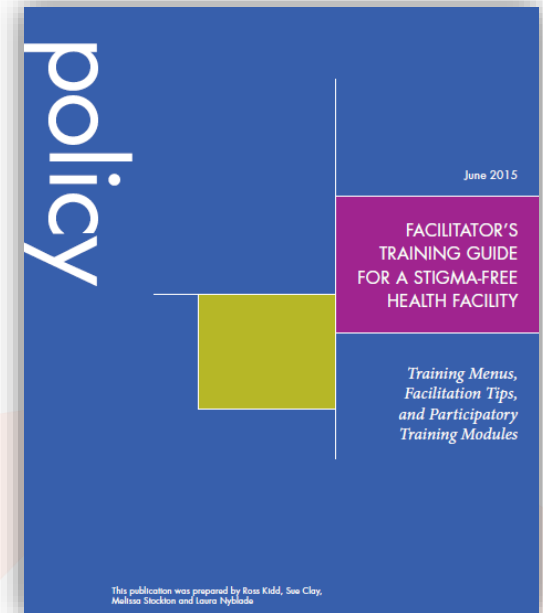
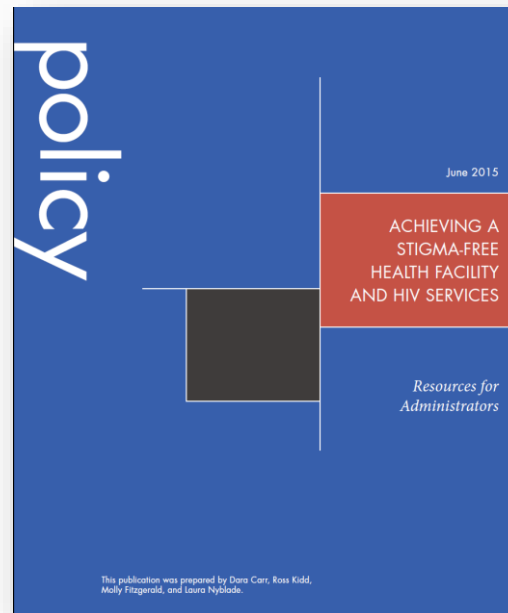
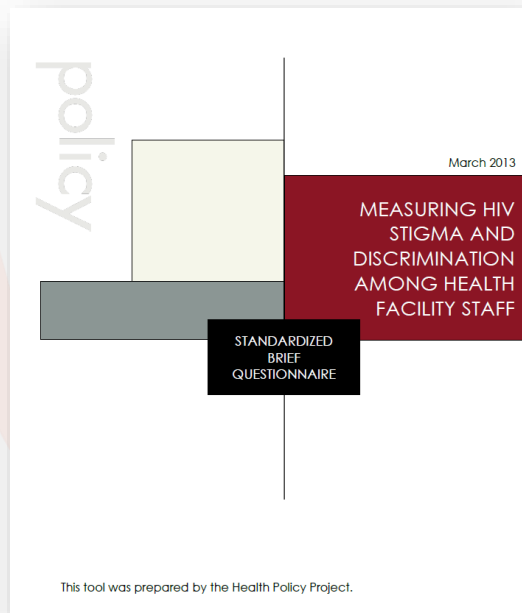
- Refusing to provide treatment
- Gossip or verbal abuse
- Differential treatment
- Marking files or clothing of patients or isolating them
- Forcing diagnostic testing on people
- Disclosing someone's HIV status
- Excessive use of barrier precautions





# MEASURING STIGMA TO END IT

# Health Policy Project



# Change Components

1. Assess

2. Train

3. Sustain



# Health Policy Project

| CHANGE COMPONENT                                                                                                      | TOOLS                                                                                                                                                                                       | AVAILABILITY                                                                                                                                                                                                                  |
|-----------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>ASSESS</b><br>Measure and understand HIV stigma and discrimination in the facility                                 | <ul style="list-style-type: none"> <li>Checklist for a Stigma-free Facility Environment and Policies for HIV stigma and discrimination</li> <li>Questionnaire for facility staff</li> </ul> | <ul style="list-style-type: none"> <li>Checklist is in this guide</li> <li>Staff questionnaire is in Annex A and on the HPP website</li> <li>User's guide for implementing the questionnaire is on the HPP website</li> </ul> |
| <b>TRAIN</b><br>Conduct participatory training to raise awareness and change attitudes and behaviors                  | <ul style="list-style-type: none"> <li>Menu of training programs for different types of staff</li> <li>Modules with instructions and exercises</li> </ul>                                   | <ul style="list-style-type: none"> <li>Menu of training programs is in Annex B and on the HPP website</li> <li>Full collection of modules is on the HPP website</li> </ul>                                                    |
| <b>SUSTAIN</b><br>Develop and mainstream action items and policies to sustain a stigma-free facility and HIV services | <ul style="list-style-type: none"> <li>Code of Conduct</li> <li>Action Plan</li> </ul>                                                                                                      | <ul style="list-style-type: none"> <li>Code of Conduct tool in this guide</li> <li>Action Plan tool in this guide</li> </ul>                                                                                                  |

# Steps for Responding to Stigma and Discrimination

1. Set up or identify a stigma action group
2. Assess your facility
3. Review current policies and practices
4. Get ideas from community members or local organizations
5. Develop and launch a Code of Conduct
6. Mainstream stigma-free norms and practices
7. Monitor progress

# Audience Polling

Have you ever stigmatized or discriminated against another person while delivering health care services?

- Yes
- No

# Audience Polling

Do you believe that People Living with HIV experience stigma and discrimination in the healthcare system?

- Yes
- No

# Assess

- Checklist
  - Assessment of the ability to support and deliver stigma-free HIV services
  - Six domains: Equal Access, Confidentiality, Safety, Training, Quality Assurance, Policy
- Comprehensive Brief Staff Survey
  - Validated survey, available in multiple languages
  - Measures health care and provider stigma

# Five Domains of the Comprehensive Tool

**Infection control**  
(fear of HIV transmission & avoidance behaviors)

**Opinions about PHLIV and Key Populations**  
(willingness to treat)

**Health facility environment**  
(supplies, training, policies)

**Enacted stigma**  
(self-reported avoidance behaviors, observed and secondary stigma)

**Special Module:**  
pregnant women living with HIV

# Train

- HUGE training program
- Multiple modules appropriate to all levels of staff and volunteers
- Suggested agenda, handouts, and clear instructions



# Sustain

- Code of Conduct
  - Set of agreed upon policies and procedures that guide staff behavior
  - Most effective when developed collaboratively
  - Development instructions available at the Health Policy Project
- Action Plan
  - The implementation of the Code of Conduct

# Sample Action Plan Item

| WHERE WE ARE NOW (CHALLENGES)                                                                | WHERE WE WANT TO BE (RELEVANT CODE OF CONDUCT ITEM/S)                 | ROOT CAUSE(S) FOR CURRENT SITUATION                                           | RECOMMENDED ACTIONS/QUALITY ASSURANCE                                                                           | STAFF LEAD/S AND TARGET COMPLETION DATE |
|----------------------------------------------------------------------------------------------|-----------------------------------------------------------------------|-------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|-----------------------------------------|
| Sex workers are viewed as troublemakers and are often made to wait longer than other clients | All clients receive the same high-quality care without discrimination | Moral judgments and blame<br><br>Belief that other clients are more important | Train health facility staff on the needs of sex workers—and how to provide appropriate services and information | Name/Date                               |
|                                                                                              |                                                                       |                                                                               | Assess training through pre- and post-surveys of participants                                                   | Name/Date                               |
|                                                                                              |                                                                       |                                                                               | After training, gather feedback from clients or client representatives about experiences in the facility        | Name/Date                               |

# Change Components

1. Assess
2. Train
3. Sustain



# Review: Primary Drivers of Stigma and Discrimination

- Limited recognition of stigma and discrimination
- Fear of acquiring HIV through casual contact
- Moral judgements and values



Why?

# Where to start?



# Questions?

# Comments?

# Contact Information



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