

Understanding and Addressing Stigma in Healthcare Settings

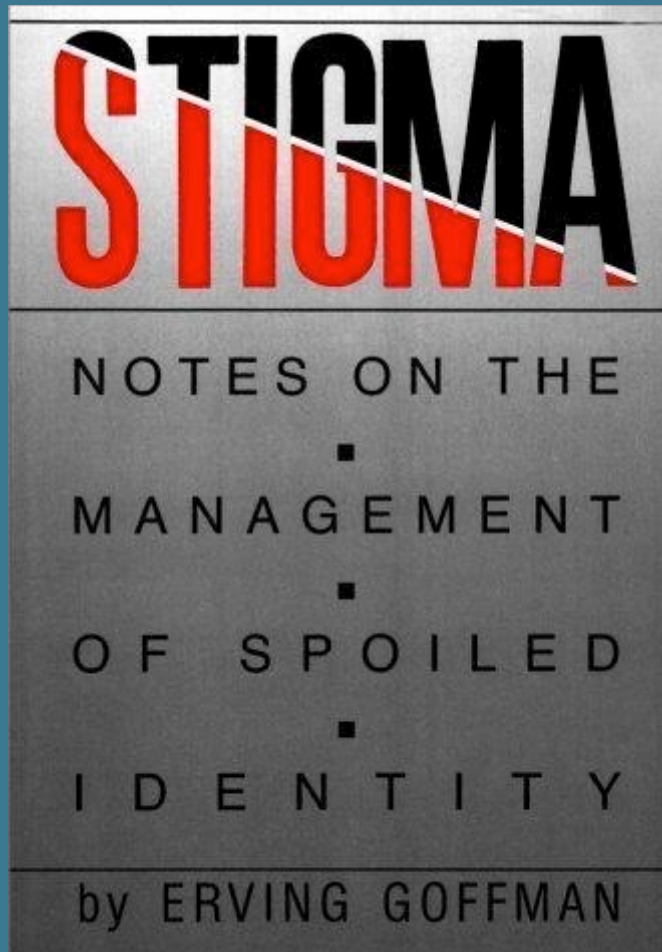


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Session Objectives

- At the end of the session, participants should be able to:
 - Define types and dimensions of stigma.
 - Explain how HIV-related and intersectional stigma experienced by clients can affect HIV prevention and treatment behaviors, as well as health outcomes.
 - Identify the variety of interventions and tools that can be used in healthcare settings to reduce stigma.
 - Describe the Finding Respect and Ending Stigma around HIV (FRESH) intervention methods and pilot results.

What is Stigma?



- Attributes or behaviors that can cause individuals to *lose social value*
- an attribute that is “deeply discrediting”
- Reduces a person from being a whole and usual person to a “tainted, discounted one”

Health-related Stigma

- “a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem”

(Weiss and Ramakrishna, Lancet, 2006)

Examples of stigmatized health conditions/behaviors

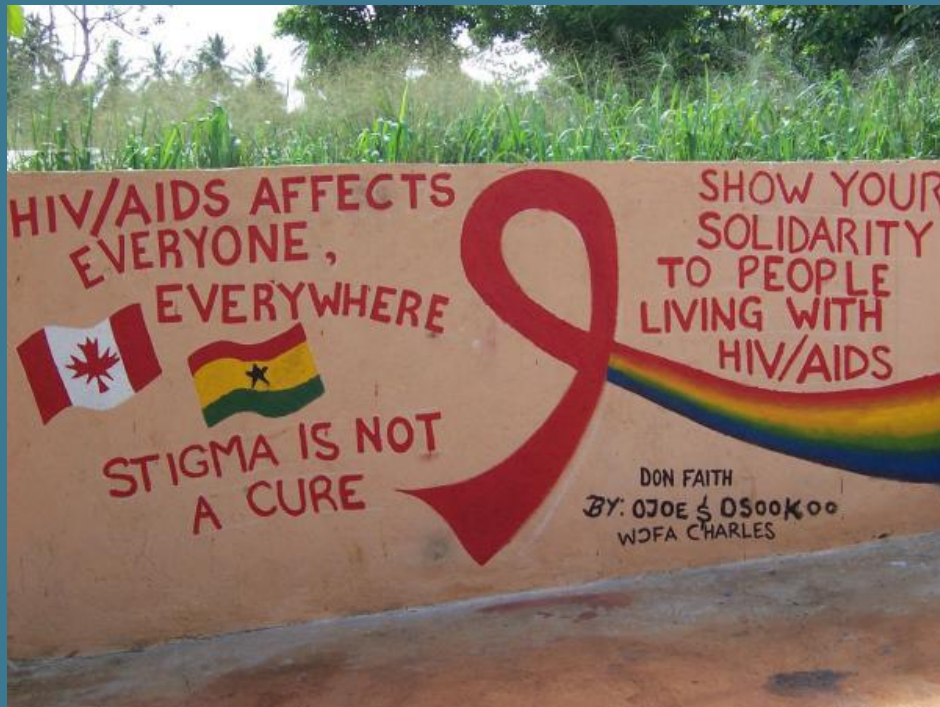
- HIV
- Tuberculosis
- Obesity
- Mental illness
- Substance abuse disorders
- Smoking



Dimensions/types of stigma

- Anticipated stigma (fears)
- Normative stigma (perceptions of community norms)
- Experienced or enacted stigma (discrimination)
- Internalized or self stigma

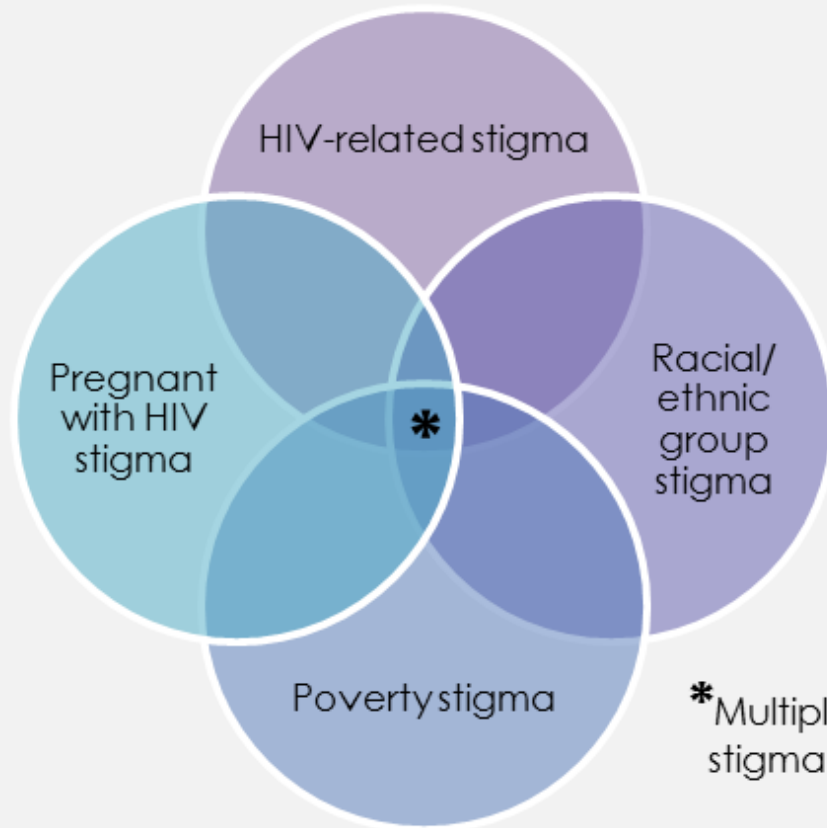
HIV-Related Stigma and Discrimination Persist **Globally** and **Locally**



* Photo courtesy of Dr. Bronwen Lichtenstein, UA

Intersectional Stigma

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

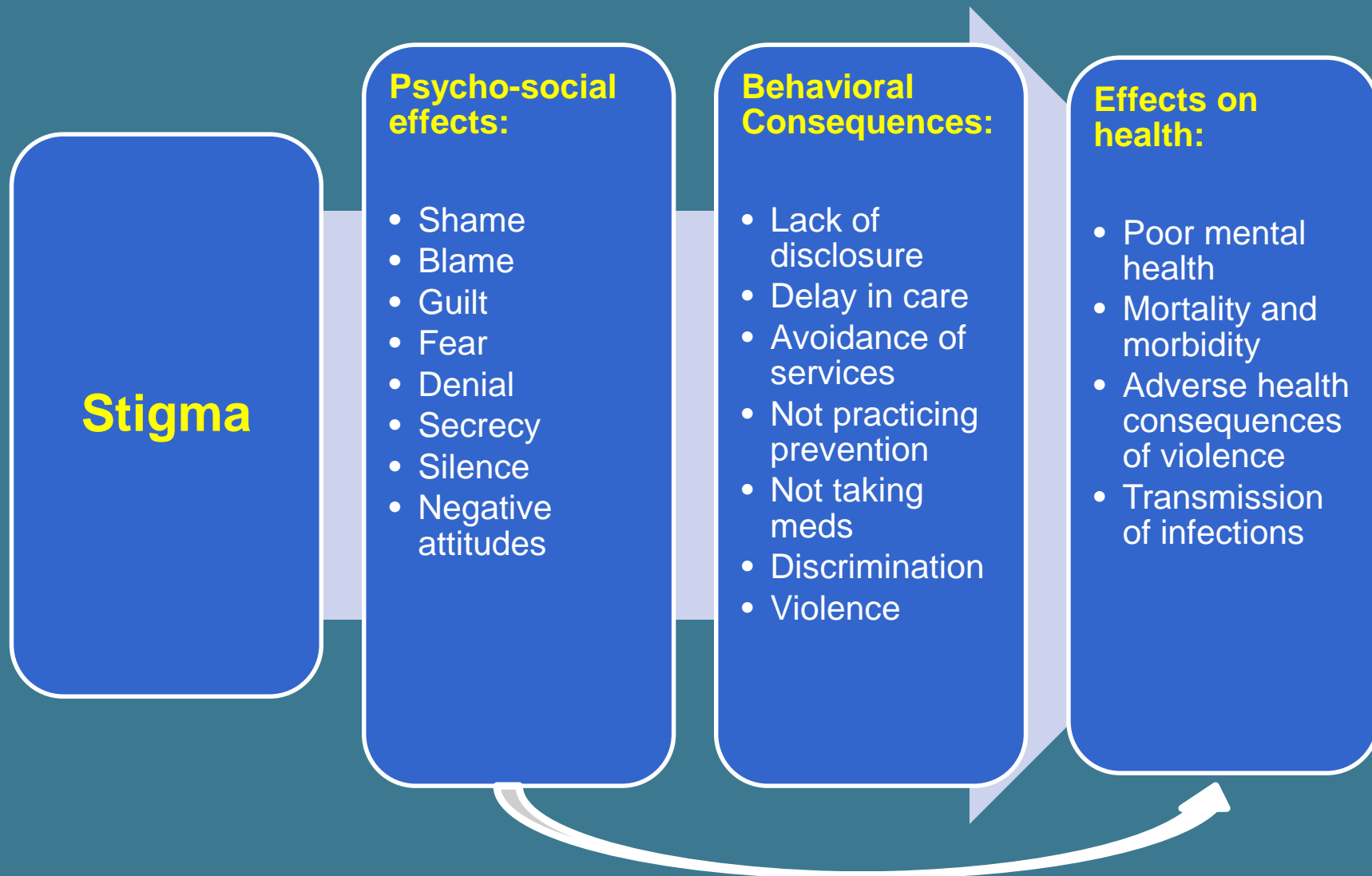


* Multiple experiences of stigma and discrimination

How can stigma affect health?

- Stigma adversely affects **quality of life and physical and mental health** of persons with stigmatized conditions
- Stigma and fears of stigma make people **less likely to practice preventive behaviors and/or utilize needed health services**
- Stigma can lead to **discrimination and violence**, with adverse consequences for health

A framework for the effects of stigma on health



What is known about the effects of HIV-Related Stigma?

Qualitative and mainly cross-sectional studies have found that HIV-related stigma is associated with poor engagement in HIV care and ART adherence*, including:

- Lower acceptance of HIV testing
- Lower access to medical care
- Poorer ART adherence
- Lower utilization of HIV care



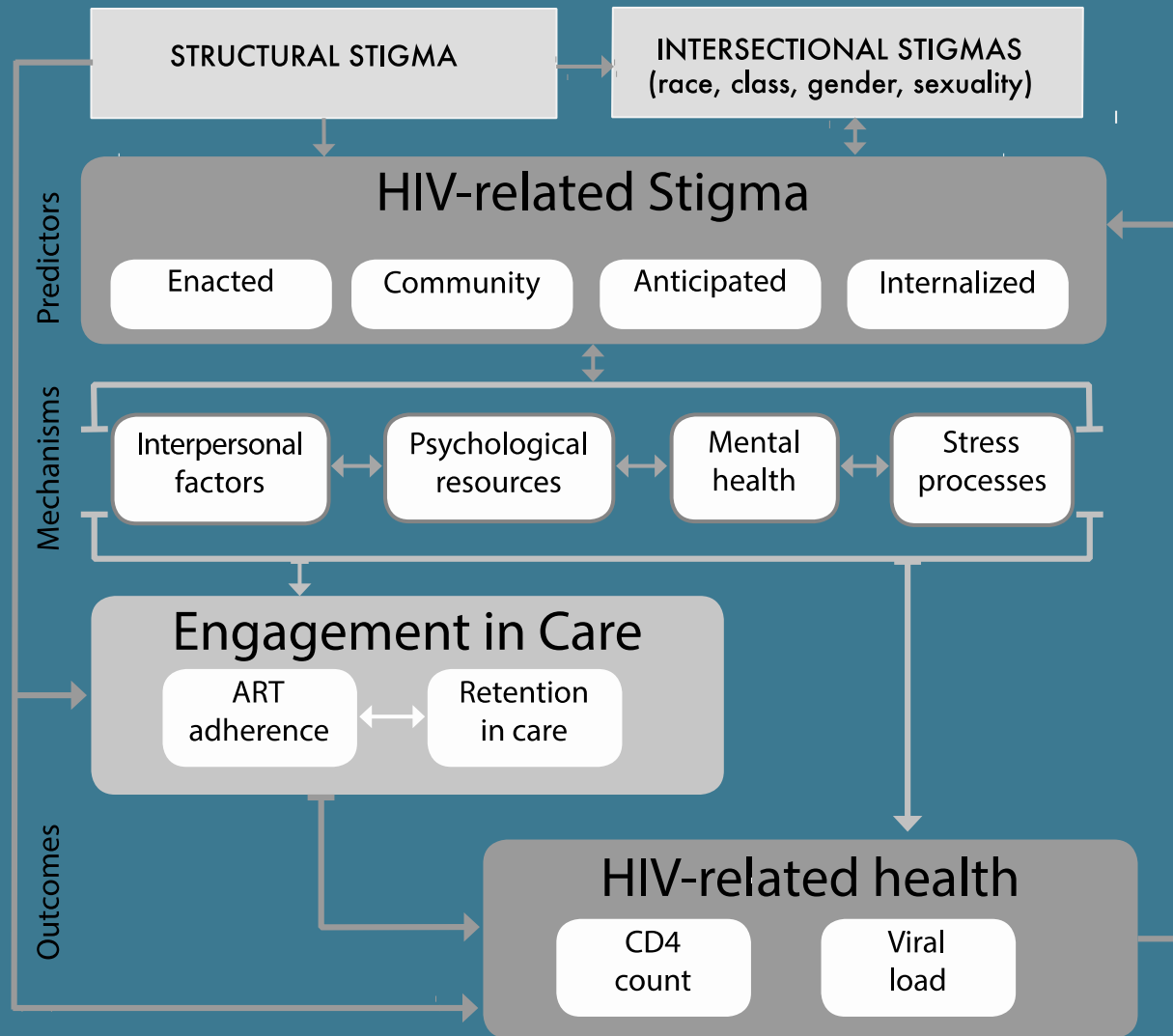
*Katz et al., JIAS, 2013; Sweeney and Vanable, AIDS Behav, 2016.



Disparities and HIV-Related Stigma

- *Could differences in experiences and effects of stigma (including intersectional stigma) help explain disparities in HIV outcomes by gender, sexual orientation, and race/ethnicity?*
 - Women of color are at particularly high risk of acquiring HIV, and have worse health outcomes once infected compared to White women.
 - HIV-infected women have lower ART adherence, lower retention, and higher mortality compared to men.
 - Young black MSM have the highest rates of new HIV infections and worst outcomes in the US.

A Conceptual Framework*



*B. Turan et al., Framing Mechanisms Linking HIV-Related Stigma, Adherence to Treatment, and Health Outcomes, *American Journal of Public Health*, 2017.

Experienced Stigma and Stress

- Experienced stigma may lead to chronic stress, which may affect physical health of PLWH (e.g., CD4 counts and viral load)
- Mechanism: stress-responsive biological systems (e.g., the hypothalamic–pituitary–adrenal axis, sympathetic nervous system)

What do we know about HIV-related stigma in the United States and specifically in the South?



HIV STIGMA IN THE US

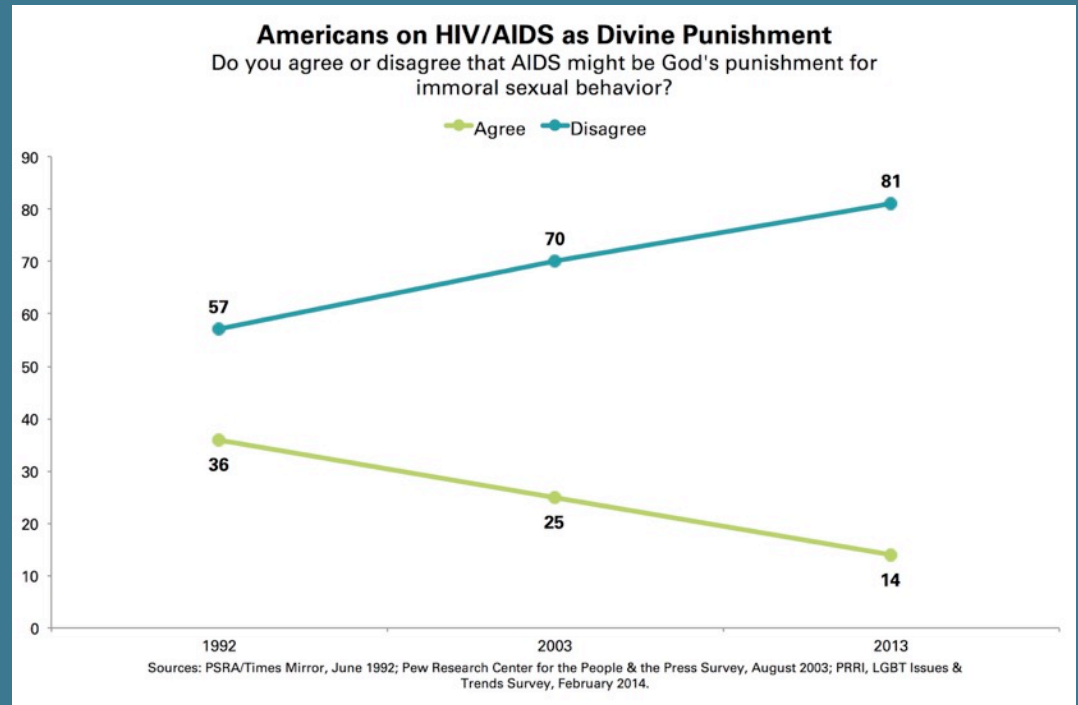
Less stigma?

HIV stigma has declined over the past 20 years. That's good news, right?

Not quite

HIV has lost some of its power to instill fear, because it is no longer seen as a potential threat to everyone.

However, stigma still serves as a barrier to HIV diagnosis, prevention, and access to care.



Stigmatizing Attitudes at Project F.A.I.T.H. Churches in South Carolina

(Lindley et al., Public Health Reports, 2010)

Table 3. HIV-related stigma among Project F.A.I.T.H. parishioners, pastors, and care team members, South Carolina, 2007

	Parishioners	Pastors	Care team
<i>Statements regarding HIV</i>	<i>Percent disagreeing with statement</i>		
AIDS is a punishment from God for sin. ^a	75.4	87.7	91.0
People who inject drugs deserve to get AIDS. ^a	84.1	94.9	98.2
Homosexuals deserve to get AIDS. ^a	81.3	93.2	98.2
Most people with AIDS only have themselves to blame. ^{a,b}	68.5	69.5	86.5
I have little sympathy for people who get HIV from sexual promiscuity. ^a	72.2	86.4	91.8
	<i>Percent agreeing with statement</i>		
People with AIDS should be treated with the same respect as anyone else. ^{a,c}	82.7	94.9	96.4

Silent Endurance and Profound Loneliness in the Rural South

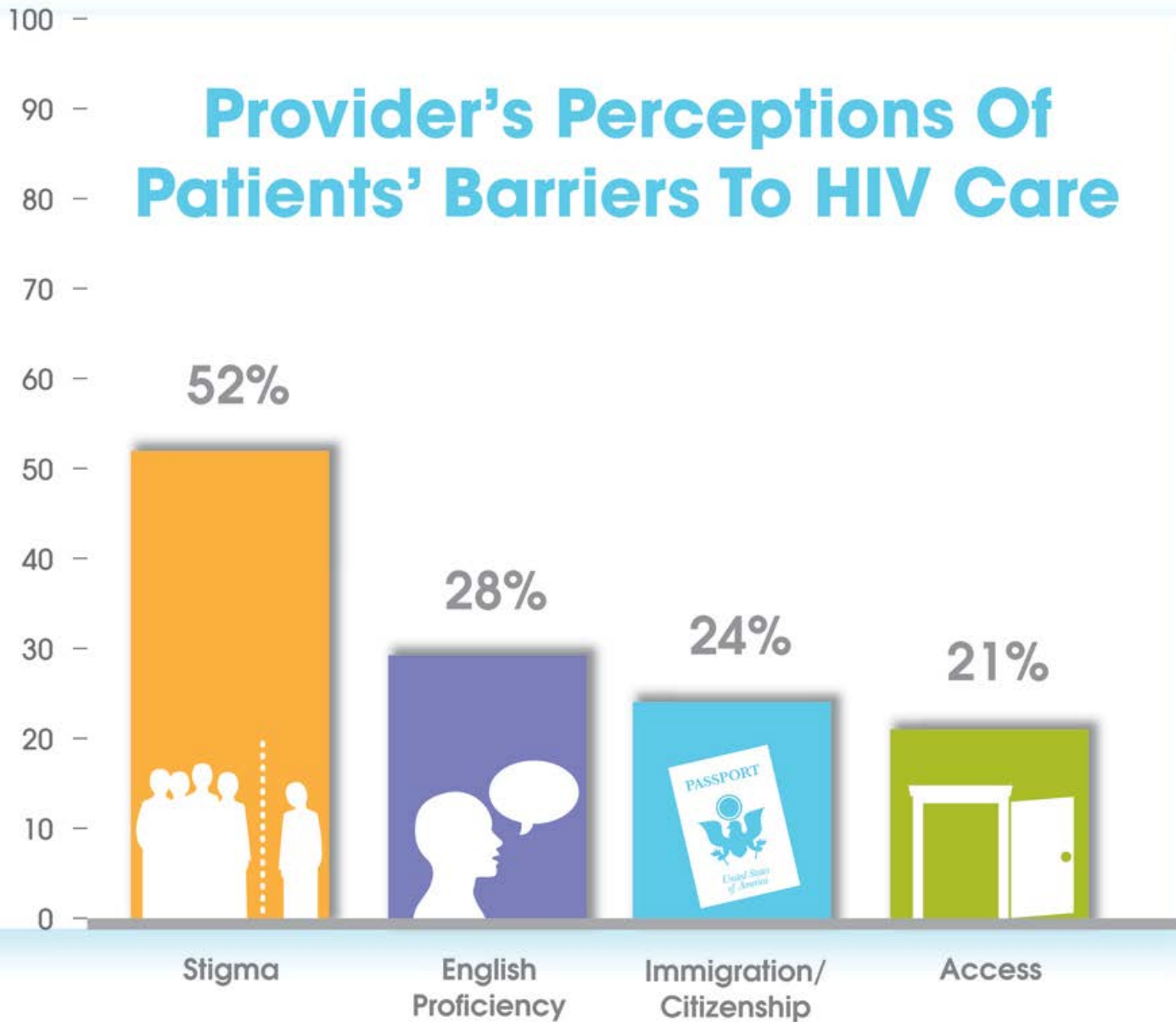
(Miles, et al., Qual Health Research, 2010)

“They don’t want [people with HIV] to come in their house . . . don’t want to touch them . . . don’t want to sit beside them. Hearing comments like that . . . I want to explain to them and tell them what’s going on, but I don’t. I just back down because I think that they’re going to say the same thing about me”.

“They talk about you like a dog. People are just uncaring, insensitive . . . point their fingers and look down on PLWH [like] modern day leprosy.”

“They’re stigmatized because of the fact that they got HIV . . . people look down . . . I guess they figure we’re, how do you say it, degenerates.”

Provider's Perceptions Of Patients' Barriers To HIV Care



Source: 2nd Annual HealthHIV State of HIV Primary Care Survey, January 2012

Survey of Public Health and Primary Health Care Workers in the South*

Table 2 Frequencies and percent for survey measures (n = 651)

Attitudes towards PLHIV ^a	Frequency (%)		
	Agree	Disagree	Missing
People living with HIV could have avoided HIV if they had wanted to	196 (30.1)	455 (69.9)	0
HIV is punishment for bad behavior	20 (2.3)	631 (97.7)	0
Most people living with HIV do not care if they infect other people	59 (9.1)	592 (90.9)	0
People living with HIV should feel ashamed of themselves	10 (1.5)	641 (98.5)	0
Most people living with HIV have had many sexual partners	123 (18.9)	528 (81.1)	0
People get infected with HIV because they engage in irresponsible behaviors	230 (35.3)	421 (64.7)	0
Anticipated shame	Frequency (%)		
	Yes	No	Missing
I would be ashamed if I were infected with HIV	265 (40.7)	380 (58.4)	6 (0.9)
I would be ashamed if someone in my family were infected with HIV	112 (17.2)	532 (81.7)	7 (1.1)

*Stringer et al., AIDS & Behavior, 2015.

Intersecting stigmas experienced by diverse women living with HIV in the US

- Most commonly:
 - Gender
 - Race
 - Poverty
- But also:
 - Incarceration
 - Age
 - Body image

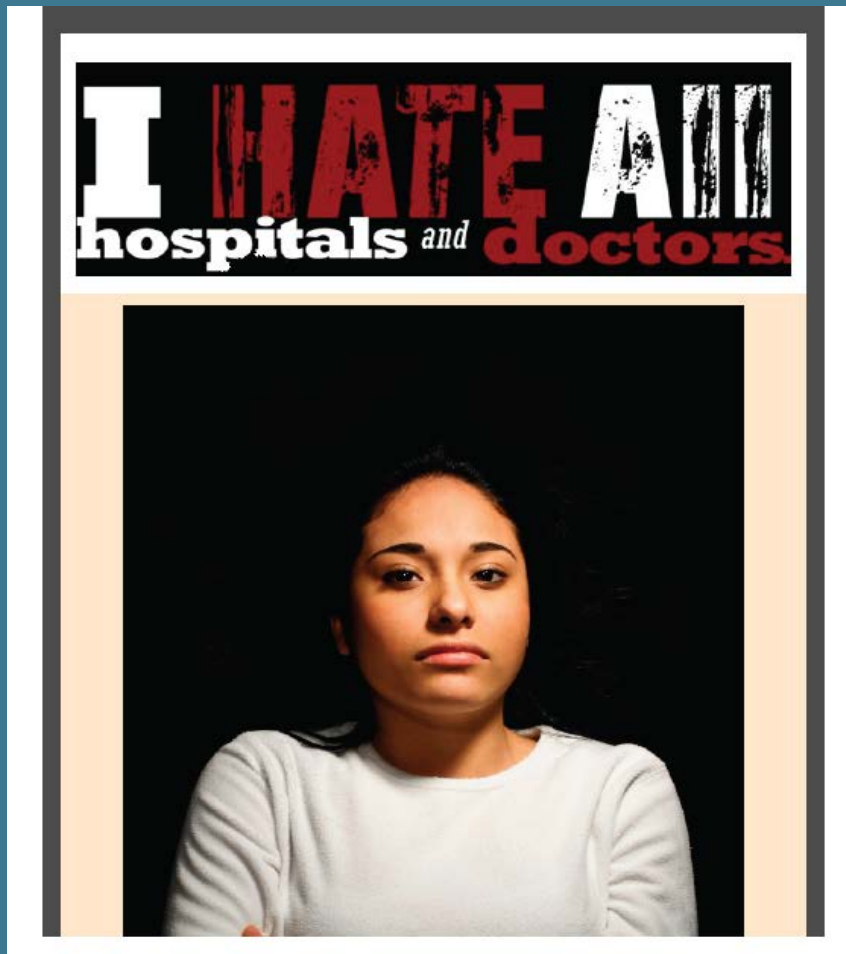
“All my life I've always wondered what people discriminated against me for. Is it because I was Black? Is it because I was biracial? I never knew if people were discriminating against me because I was HIV-positive, because I was a woman. Honestly, I don't know what. I can't like really pinpoint. I just know that something. I guess it is like a gut feeling. Something just didn't feel right. Like somebody insulted me and like later I'm like what was that for?”

Why Addressing Stigma and Discrimination in Healthcare Settings is Important

- Persons affected by HIV may have frequent contact with healthcare providers
- Fears of stigma, discrimination, and lack of confidentiality in health facilities can discourage people from:
 - accepting HIV testing / PrEP
 - linking to HIV care after receiving an HIV-positive test result
 - adhering to HIV visits and treatment, or to PrEP
 - Getting other kinds of healthcare that they need



Rebecca's story from the International Conference on Stigma*



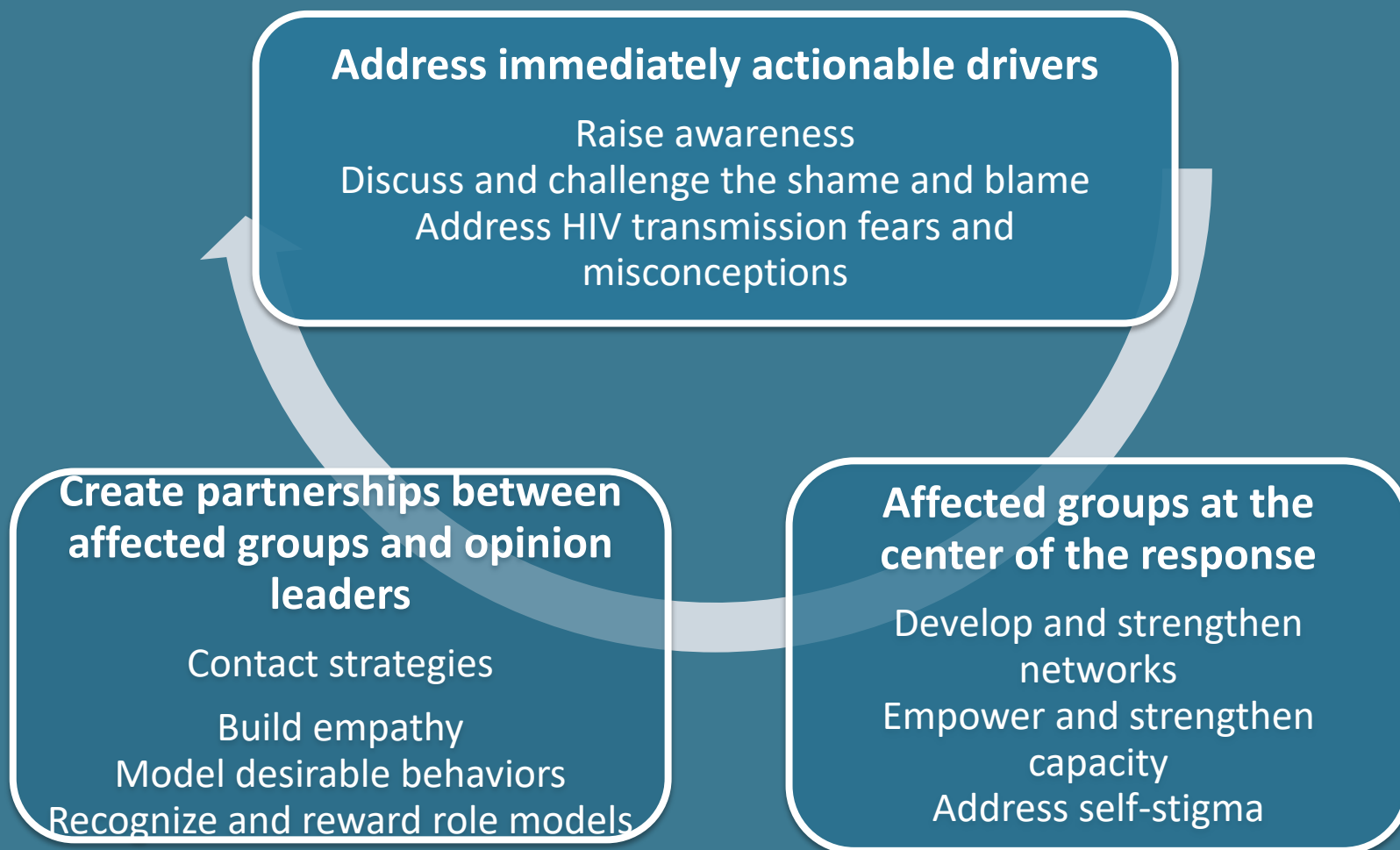
- "Once they found out I had HIV, nobody wanted to do my C-section."
- Rebecca's surgery was scheduled at 8 am. At 7 am she got the positive results of her HIV test. But then it was 9 am. And then 11 am. There was no one willing to operate on an HIV positive patient.
- "And now, every time I go to a hospital or a doctor, I get a panic attack. The feelings of being treated as untouchable come back."

Stigma in HC Settings

- Fears and experiences of stigma in healthcare settings can both cause internalized stigma and erode trust in healthcare workers, resulting in detrimental effects for the mental and physical health of PLWH.
- Internalized HIV stigma is associated with lower antiretroviral therapy (ART) adherence.
- This association may be stronger for PLWH in racial/ethnic minority groups as compared to whites.

What can we do to reduce stigma in healthcare settings??

Key Principles for HIV Stigma-Reduction Interventions*



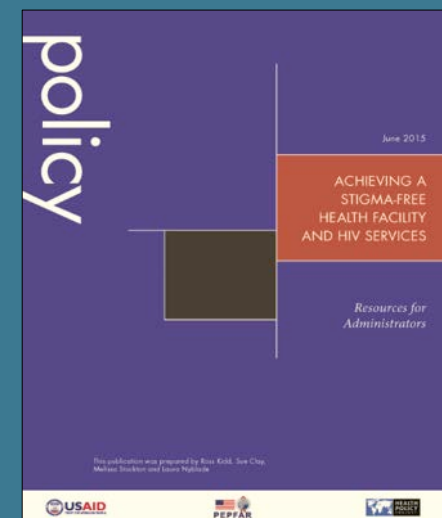
*Nyblade L, Stangl A, Weiss E, et al. Combating HIV stigma in health care settings: What works? J Int AIDS Soc 2009;12:15.

Interventions that address HIV-related and intersectional stigma in HC settings

- Interventions that work with health workers
 - Medical/nursing students, current service providers, all levels of staff in a facility
 - In-person workshops, seminars, videos, apps
- Interventions that work with clients
 - AA women, Black MSM, Transgender groups, PLWH
- Interventions that work with both
 - Multi-Country African Study
 - FRESH adaptation for the US

HPP Stigma-Reduction Package Core Components

- **Assess:** Two tools and a user's guide for implementation
- **Train:** Training menus and material for health workers
- **Sustain:** Facility assessments, action planning, examples for developing codes of conduct and facility policies



Training Package

- Based on field application in 9 countries
- Can be tailored for different health worker audiences and timeframes
- Includes 17 sample workshops and 1 refresher

Sample S&D Training Programs

Half-day workshop for health facility managers

Three-day work shops for medical health workers

Ten-week modular course for medical health workers

Three-hour workshop for doctors on stigma toward key populations

H: One-day Workshop for Doctors

Description

The one-day workshop includes an introduction to stigma in health facilities; a reflection on personalizing stigma; and an opportunity to analyze stigma in health facilities, with a view to suggesting actions for change

If possible, follow up this workshop with Workshop I, which focuses on key populations.

Target Group

Doctors

Objectives

By the end of the training, the doctors will have accomplished the following:

- Identified some of the most common examples of stigma in their own health facilities
- Discussed the forms, effects, and causes of stigma in health facilities
- Discussed further steps for helping to reduce stigma in their health facilities

Modules

NUMBER	TITLE	TIME
A1 or A4	Naming Stigma in Health Facilities Through Pictures; or Naming Stigma in our Health Facility (Case Studies)	1 hour
A2	How Stigma Feels (Reflection Exercise)	
A3	Effects of Stigma on the HIV Epidemic	1 hour
B4	Exploring Beliefs and Attitudes About PLHIV and Other Key Populations (Value Clarification Exercise)	1 hour
A6	Analyzing Different Forms of Stigma in Health Facilities	1 hour
E	Developing a Code of Conduct for a Stigma-free Health Facility	1 hour



The FRESH Study (Finding Respect and Ending Stigma around HIV)

- Increasing our knowledge about levels and effects of HIV-related stigma in the South
 1. At-risk populations
 2. Health care providers
 3. Persons living with HIV (PLHIV)
- Adapting and piloting an intervention originally developed in Africa to reduce stigma and discrimination in healthcare settings in the South

Collaborating Partners

- UAB Center for AIDS Research (CFAR)
- Alabama Public Health Training Center
- UAB School of Public Health
- Alabama Department of Public Health
- Jefferson County Department of Health
- Health Services Center, Hobson City, AL
- Birmingham AIDS Outreach (BAO)
- Alabama Primary Health Care Association
- UAB Deep South CME Network

The FRESH Stigma Reduction Intervention for Health Workers and PLHIV

(based on Uys et al., 2009)



- **sharing information**
 - Sharing the results of local data collection on HIV-related stigma and giving general information about the impact of stigma on PLHIV
- **increasing contact with the affected group**
 - bringing together a group of health workers and PLHIV to plan stigma-reduction activities together
- **improving coping through empowerment**
 - engaging PLHIV in an activity in which they can address stigma directly, not just accept or live with it

FRESH Workshop Intervention

- ~10 health workers
 - Nurses, social workers, receptionists, disease intervention specialists, etc.
- ~10 community participants (persons living with HIV)
- Facilitated by one health worker (social worker) and one client (PLHIV)
- 1.5 days (on the weekend)
- In a neutral location

FRESH Workshop Objectives

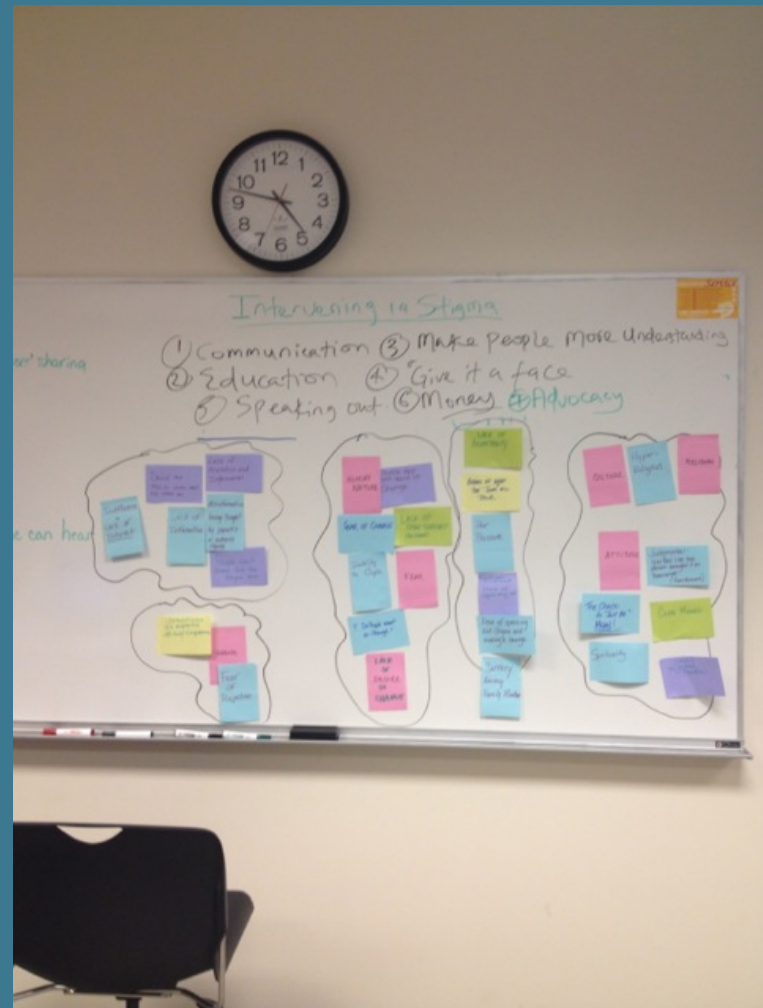
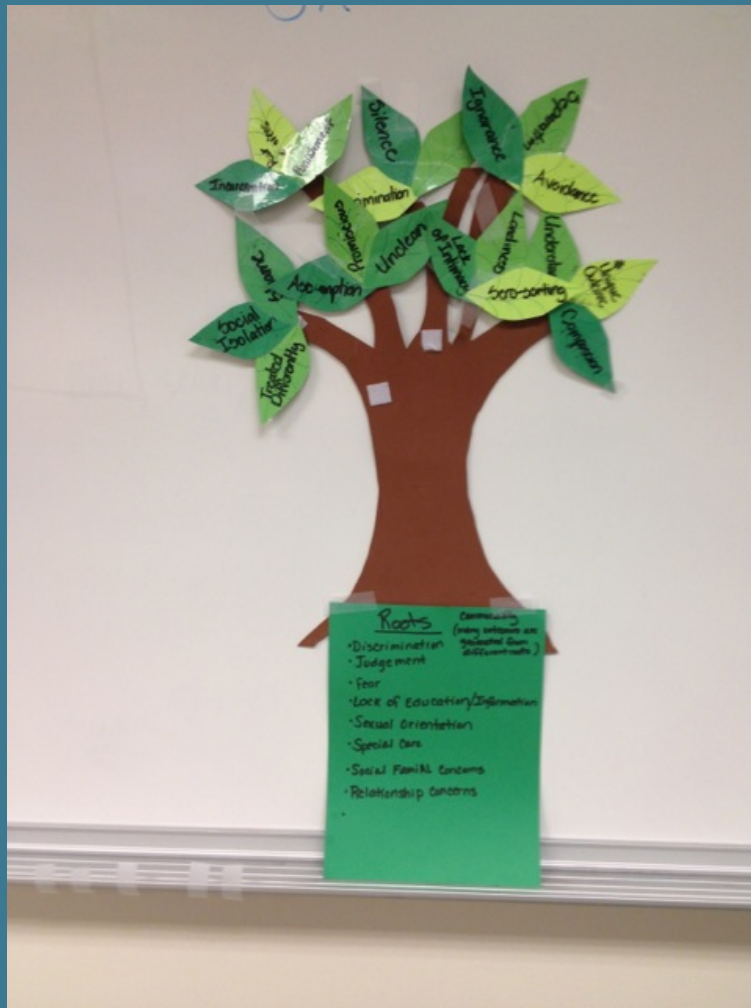
- Provide contact and collaboration opportunities for participants to mutually understand stigma and their stigma experiences
- Sensitize participants to their stigma experiences and strategies for coping with and challenging stigma
- Plan local activities that can be used to increase awareness and reduce stigma among the larger population public health and primary healthcare workers

FRESH Workshop Agenda

- Understanding Stigma
 - Exercise: Roots and Leaves
- Intersecting Stigmas
 - Exercise: Stigma stories
- Outcomes of Stigma
 - Lunch and HIV Knowledge Update
- Challenging and coping with Stigma
 - Exercise: Why is Stigma Hard to Change
- Stigma reduction strategies
 - Activity: Working together to plan activities to reduce stigma in the healthcare settings



Workshop Activities



Pre- and Post-Questionnaires

Health Workers:

- Socio-demographics
- Stigma scales
- Discrimination experiences (race, gender, etc.)
- Risk perception
- HIV knowledge
- Empathy
- Contact
- Workshop experience

Community participants:

- Socio-demographics
- Patient empowerment
- HIV-related self-efficacy
- Stigma scales
- Discrimination experiences (race, gender, etc.)
- Self esteem
- Coping
- Workshop experience

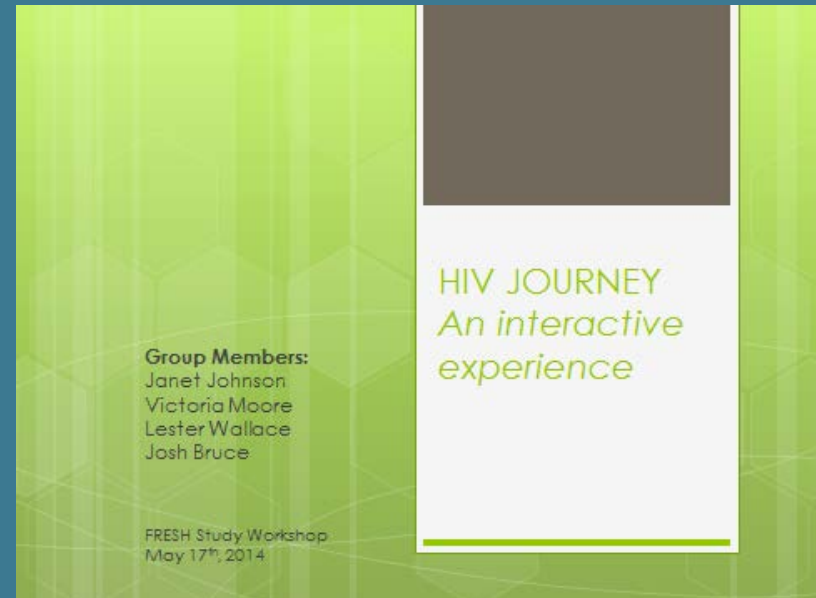
Initial FRESH Workshops in Birmingham

May and September 2014

- **Workshop #1:** 13 participants (7 HWs, 6 PLHIV, some overlap)
- **Workshop #2:** 23 participants (11 HWs, 12 PLHIV, some overlap)
- Health worker participants from local department of health, state department of health, AIDS service organizations, university clinics, etc.

Project activities for reducing stigma in healthcare settings

- Some of the activities developed:
 - Interactive workshops with medical students
 - TED Talks
 - Role play experiences with nursing students



FRESH pilot results*

- **Satisfaction** with the workshop experience was high
 - 87% PLWH and 89% HW rated the workshop “excellent”
- **Content analysis** of open-ended items revealed that participants felt that the workshop:
 - Was informative, interactive, well-organized, understandable, fun, and inclusive
 - Addressed real and prevalent issues
- Although sample sizes were small, **positive trends in pre-post test measures** were observed:
 - increased awareness of stigma in the health facility among HWs (p=.047)
 - decreased uncertainty about HIV treatment among PLWH (p=.017)

Batey DS, Whitfield S, Mulla M, Stringer KL, Durojaiye M, McCormick L, Turan B, Nyblade L, Kempf MC, **Turan JM**. Adaptation and Implementation of an Intervention to Reduce HIV-Related Stigma Among Healthcare Workers in the United States: Piloting of the FRESH Workshop. *AIDS Patient Care and STDs*, 2016.

FRESH Continues....

- Currently collecting baseline data from clients and providers at 6 HIV clinics across Alabama and Tennessee (Batey, CFAR funding), with plans to further adapt and test the intervention at these sites
- Proposal to adapt FRESH for the Dominican Republic (Budhwani, pending)
- Workshop materials are available through the Alabama-Mississippi Public Health Training Center website <http://alphtc.org/fresh>

FRESH Acknowledgements

- Research participants!
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 - Health Services Center
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 - Jason Leger
 - Kristi Stringer
 - Cathy Simpson
 - Ruth DeRamus
 - D. Scott Batey
 - Melonie Walcott
 - Samantha Whitfield

Getting to Zero

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**ZERO NEW HIV INFECTIONS.
ZERO DISCRIMINATION.
ZERO AIDS-RELATED DEATHS.**