

Addressing Stigma Related to HIV and Other Sexually Transmitted Infections

**Satellite Conference and Live Webcast
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**Produced by the Alabama Department of Public Health
Video Communications and Distance Learning Division**

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Objectives

- 1. Explain how stigma and discrimination can adversely affect health behaviors and health outcomes**
- 2. Describe what is known about levels and experiences of stigma related to HIV and Sexually Transmitted Infections (STIs) in the United States**

Objectives

- 3. Discuss why addressing stigma and discrimination in public health and other healthcare settings is especially important**
- 4. Describe tools and methods for measuring and reducing stigma and discrimination related to HIV and STIs**

Objective I:

Explain How Stigma and Discrimination Can Adversely Affect Health Behaviors and Health Outcomes

What Is Stigma?

- When individuals lose social value due to having certain attributes or behaviors

Health-related Stigma

- 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

Health-related Stigma

- Examples of stigmatized health problems:
 - HIV/AIDS
 - Tuberculosis
 - Obesity
 - Mental illness
 - Substance use disorders
 - STDs

Dimensions / Types of Stigma

- Anticipated stigma
 - Fears
- Normative stigma
 - Perceptions of community norms
- Experienced or enacted stigma
 - Discrimination
- Internalized or self stigma

“Perpetrators” of Stigma

- The wider community
- Service providers
- Family
- Intimate partner
- Self
- Institutions
 - Schools, churches, health facilities?

Stigma Associated with HIV and STIs

- Fear of contagion
- Association with death (HIV)

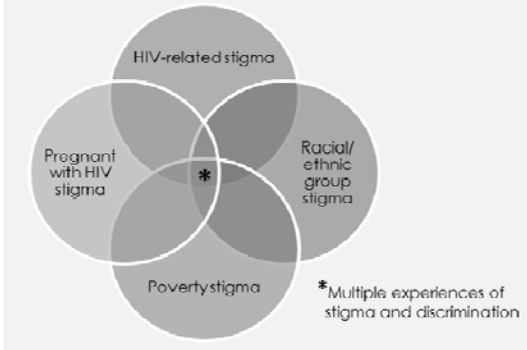
Stigma Associated with HIV and STIs

- Association with marginalized behaviors
 - Promiscuity
 - Illegal drug use
 - Men who have sex with men
 - Prostitution

Intersection of HIV-related Stigma with Other Stigmatized Identities

- Sex workers
- Men who have sex with men
- Injection drug users
- People with multiple sex partners
- Poor people

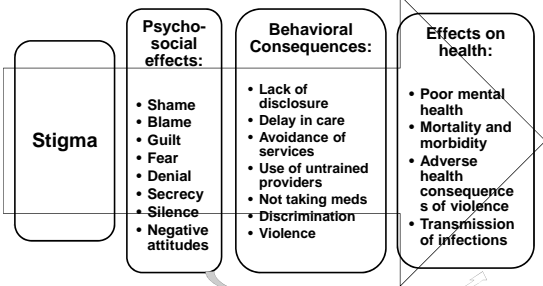
Overlapping Stigmas Experienced by Poor Women in Marginalized Racial/Ethnic Groups Living with HIV



Stigma and Health

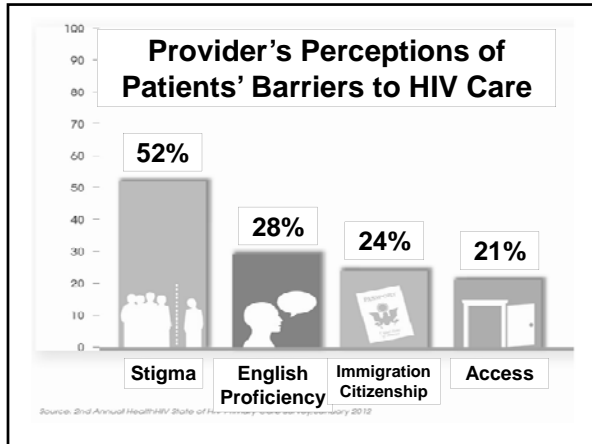
- How does stigma affect health?
 - Stress
 - Mental health
 - Testing
 - Disclosure
 - Seeking care
 - Quality of care
 - Quality of life

Framework for Effects of Stigma on Health



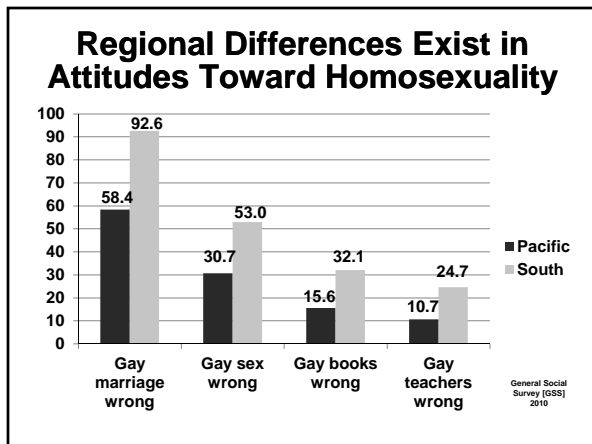
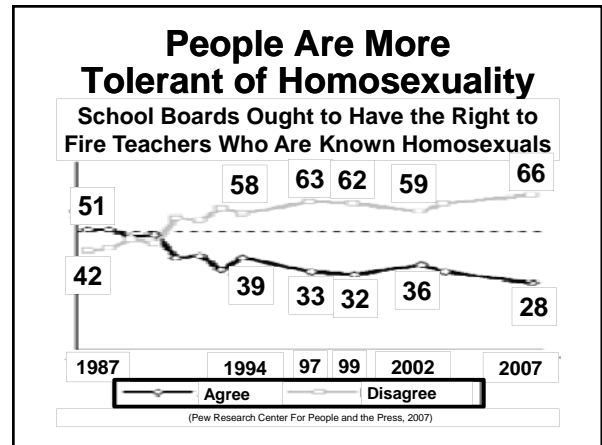
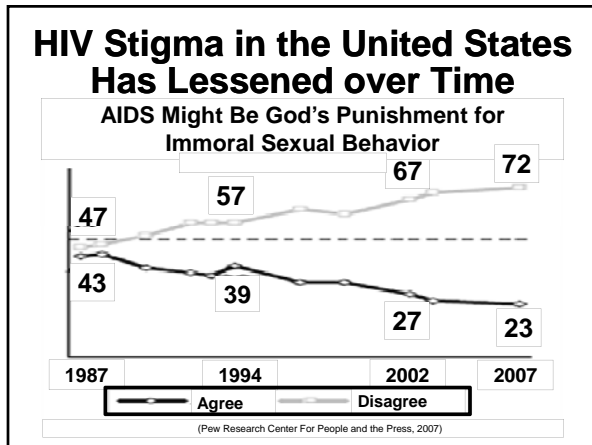
For HIV and STIs, Fears of Stigma Can Result In:

- Avoidance of testing
- Not going for treatment after receiving a positive test result
- Not adhering to follow-up visits and treatment recommendations
- Not getting other kinds of healthcare that are needed



Objective II:

Describe What Is Known About the Levels and Experiences of Stigma in the United States



Why Regional Differences Matter

- HIV/AIDS rates are higher in the south
 - “The AIDS Belt” comprises all southeastern states from Maryland to east Texas

Why Regional Differences Matter

- The south (The Bible Belt) is socially conservative and racially divided
 - The percentage of African Americans is higher than in other U.S. regions

Why Regional Differences Matter

- HIV stigma is expressed in conspiracy theories, distrust of mainstream medicine, religiosity, homophobia, sex education, and racial identity

HIV Stigma Reflects a Racialized Past

Mistrust of "system"

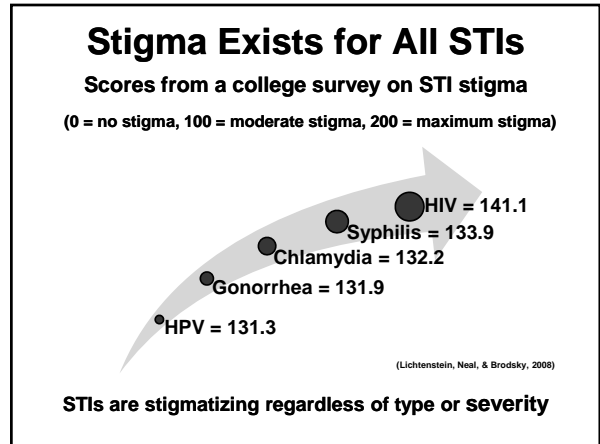
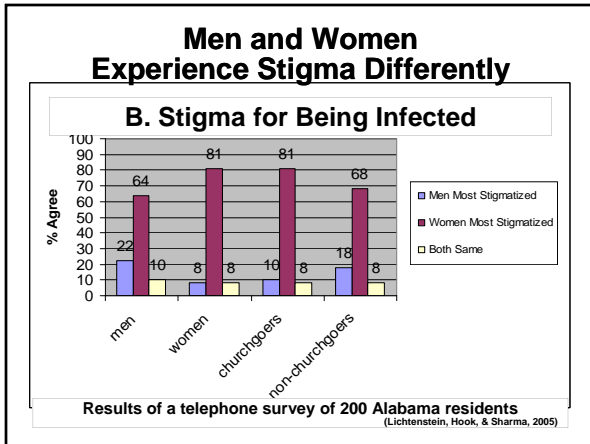
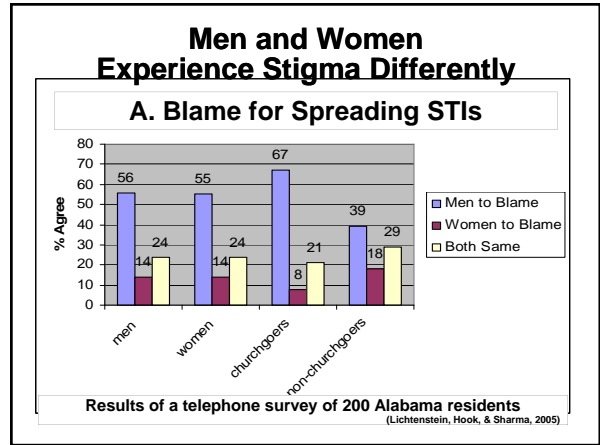
- Blacks are singled out for blame
- Black men don't go to the doctor

Conspiracy theories

- The government invented AIDS to wipe out the Black race
- Needle exchange programs boost drug use among Blacks

Religiosity/homophobia

- AIDS is God's punishment for sin
- White sexual mores corrupt Black youth



Objective III:

Discuss Why Addressing Stigma and Discrimination in Public Health and Other Healthcare Settings Is Especially Important

Two Types of Stigma Interfere with STI / HIV Care

- Type one
 - Community stigma
- Type two
 - Stigma in healthcare settings

Two Types of Stigma Interfere with STI / HIV Care

- Both types of stigma are a barrier to care because of:
 - Damaging gossip in the community
 - Fear of being seen at the clinic
 - Being disrespected or “outed” by health workers

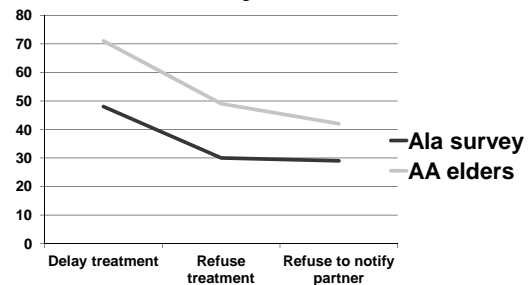
Two Types of Stigma Interfere with STI / HIV Care

- Seeking STI / HIV care can be nerve-racking on many levels

Stigma Is a Barrier to STI / HIV Care

- The following six slides provide evidence of stigma as a barrier to STI/HIV care from:
 1. Two telephone surveys of Alabama residents on STI / HIV-related attitudes
 - Adults <50 (n = 200)
 - Adults >50 (n = 190)
 2. One survey of 289 college students on STI / HIV-related attitudes

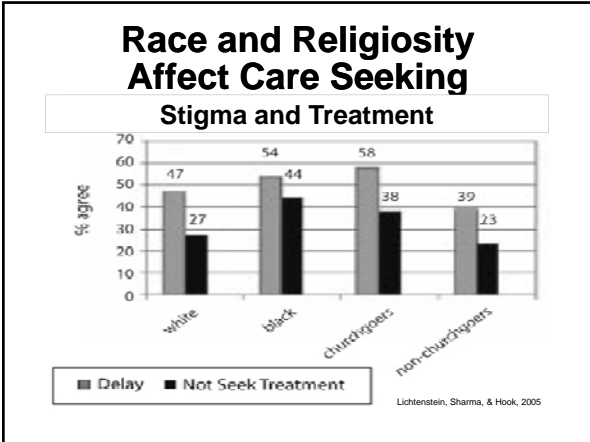
Many Alabama Adults Would Delay STI / HIV Care



Many College Students Do the Same

On a scale of 1-10, how likely is it you would:

Lichtenstein, Neal, & Brodsky, 2008	Mean Score
Blame someone if they acquired a STI	5.03
Feel ashamed if you acquired a STI	8.35
Fear becoming ill from your infection	7.81
Be willing to seek treatment	4.03



Stigma Affects Partner Notification

Lichtenstein, Hook, & Sharma, 2005	Yes	No
I would be reluctant to name my partner to a health provider because I fear what it would do to my relationship	45	52

Stigma Affects Partner Notification

Lichtenstein, Hook, & Sharma, 2005	Yes	No
I would refuse to disclose name of partner out of embarrassment	29	70

Stigma Affects Partner Notification

Lichtenstein, Hook, & Sharma, 2005	Yes	No
I am afraid of what my partner would do to me if I disclosed his or her name	18	80

- ### Clinics Can Attract Stigma
- The following slides cover a range of experiences among clients at STI / HIV clinics
 - The main problems related to being seen at the clinic (community stigma) and being disrespected by staff (clinic attitudes)

Clinics Can Attract Stigma

- Clinic employees should be aware that STIs are so stigmatizing that everything they say and do can be viewed through the lens of discrimination or moralistic attitudes

Clients Are Fearful of “Inside” and “Outside” Stigma

- General problems
 - Visibility when entering the clinic or in the waiting area
 - “Patient spotting” is a local sport

Clients Are Fearful of “Inside” and “Outside” Stigma

- What men fear
 - Being named by vengeful partners
 - Being labeled as gay
 - Being pursued by Disease Intervention Specialists (DIS)

Clients Are Fearful of “Inside” and “Outside” Stigma

- What women fear
 - Being portrayed as dirty or promiscuous

Patient Spotting Is a Problem at Clinics

- This problem particularly affects people in small towns and rural counties:
 - “The neighbors know that you’re there. They recognize you or they recognize your car.”

Patient Spotting Is a Problem at Clinics

- “The health department is a social gathering place. Everybody goes through the STD clinic to see who’s who and what is what.”
- “They come through there with their cell phones and take photos to send to their friends.”

– Lichtenstein, 2003

Patient Spotting Is a Problem at Clinics

- One way to avoid being spotted is to attend a clinic in another town or county

– Lichtenstein, 2003

Staff Attitudes Can Also Be a Problem

- “If it’s something interesting, they all come to look. Like, if you come with another woman they think you are bisexual.”

Staff Attitudes Can Also Be a Problem

- “They got an attitude, like when they come to the door and call your name. They stand there and roll their eyes. I’ve had a couple of them do that to me.”
- “I’ve had most trouble with the white ladies. One of them said, “Well, you must not care about yourself.”

Staff Attitudes Can Also Be a Problem

- “I heard one of them call me a ‘repeater.’ That’s a bad name.”

– Lichtenstein & Bachmann, 2005

STI Clients Fear Loss of Privacy

- “What does ‘confidential’ mean? When are they going to honor it because right now it doesn’t mean a thing.”
- “How did my wife know I was here the other day? Who was it in that office that told her? I can’t prove it, but you know like, who said what?”

STI Clients Fear Loss of Privacy

- “There was an elderly person there and they (staff) were discussing her out in the open. They were making jokes and laughing and talking about how she smelled and all of that. They’re not supposed to do that.”
- “The receptionist asked me about my jail record in front of everyone.”

– Lichtenstein & Bachmann, 2005

Objective IV:

Describe Tools and Methods for Measuring and Reducing Stigma and Discrimination Related to HIV and STIs

Ways to Reduce Stigma

- Help institutions recognize stigma
- Address stigma in the service environment
- Listen to people living with the condition and respond to their needs
- Use the media to show that the condition has a human face

Ways to Reduce Stigma

- Involve people living with the condition in service delivery
- Engage the community
- Engage partners and family
- Expand access to treatment

– Adapted from Pulerwitz et al., *Public Health Reports*, 2010

Measuring and Monitoring Stigma

- Validated measures exist for measuring HIV-related stigma among:
 - People living with HIV (PLHIV)
 - Health workers
 - The general public

Measuring and Monitoring Stigma

- These can be used to:
 - Assess the extent of the problem
 - Needs assessment
 - Evaluate the impact of programs and interventions meant to reduce stigma

Types of HIV Stigma-reduction Interventions that Have Been Tested

- Informational approaches
 - Providing correct information about HIV to service providers
 - Media campaigns

Types of HIV Stigma-reduction Interventions that Have Been Tested

- **Skill building**
 - Develop skills among providers to help them understand stigma and discrimination and provide empathic and non-stigmatizing and non-discriminatory services

Types of HIV Stigma-reduction Interventions that Have Been Tested

- **Counseling / support to reduce self stigma**
 - Support groups and other methods to help persons living with HIV (PLHIV) cope with stigma and reduce self stigma

Types of HIV Stigma-reduction Interventions that Have Been Tested

- **PLHIV testimonials and interactions**
 - Commonly used to bolster HIV-stigma reduction approaches

– Sengupta et al., 2011

An Intervention for Internalized Stigma

- **The Unity Workshop (PI: D. Rao)**
 - 8-hour workshop across two afternoons
 - Peer facilitated
 - Participants: African American women living with HIV

An Intervention for Internalized Stigma

- **Includes:**
 - Relaxation and self-care
 - Coping strategies
 - Viewing trigger videos

An Intervention for Internalized Stigma

- Handling potentially stigmatizing situations with family, in the workplace, and in other settings
- Role playing ways to navigate these difficult situations

An Intervention for Internalized Stigma

- To be tested using a randomized controlled trial in Chicago and Birmingham, in collaboration with UAB investigators

Why Addressing Stigma and Discrimination in Healthcare Settings Is Important

- Persons living with HIV may have frequent contact with healthcare providers

Why Addressing Stigma and Discrimination in Healthcare Settings Is Important

- Fears of stigma, discrimination, and lack of confidentiality in health facilities can discourage people from:
 - Accepting HIV testing
 - Linking to HIV care after receiving an HIV-positive test result

Why Addressing Stigma and Discrimination in Healthcare Settings Is Important

- Adhering to HIV visits and treatment
- Getting other kinds of healthcare that they need

Tool for Measuring HIV-Related Stigma in Healthcare Settings

- 15-20 minute online survey for health workers is being piloted in Alabama and Mississippi
- Covers the following domains:
 - Fears of infection on the job
 - Workplace policies and procedures

Tool for Measuring HIV-Related Stigma in Healthcare Settings

- Observations of incidents of discrimination
- Health workers' own experiences of being stigmatized
- Health workers' values and attitudes about PLHIV

Tool for Measuring HIV-Related Stigma in Healthcare Settings

- Efforts are on-going to create a shorter questionnaire
- Can be used as a needs assessment AND / OR as a pre-test and post-test measure to evaluate stigma-reduction interventions

An Intervention Approach 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

An Intervention Approach for Health Workers and PLHIV (Based on Uys et al., 2009)

- Increasing contact with the affected group
 - Bringing together a group of health workers and PLWH to plan stigma-reduction activities together

An Intervention Approach for Health Workers and PLHIV (Based on Uys et al., 2009)

- Improving coping through empowerment
 - Engaging PLHIV in an activity in which they can address stigma directly, not just accept or live with it

Getting to Zero

- Zero new HIV infections
- Zero discrimination
- Zero AIDS-related deaths