SPOILED IDENTITY:
Gay Men, HIV, and Stigma

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AGENDA

- Defining HIV stigma
- HIV stigma in a gay context
- Measuring stigma
- Interventions
Voices

• “I feel like damaged goods.”

• “I told a trick who was about to take me home about my poz+ status and that I am very healthy. He walked away and refused to speak to me the rest of the evening!”

• “I’ve experienced verbal epithets in HIV-/HIV+ dating situations.”

• “I had a massage therapist who was afraid of touching someone with HIV…me!”
Voices

• “My manager is gay and made the comment one day (not knowing my status) that he would never work with someone who is positive.”

• “I had to get help from the EEOC to be able to leave my desk to go to the bathroom when I needed to without getting written up.”

• “It’s like a punch in the gut when I read ‘D/D Free…UB2’ and Clean only!!’ in online profiles.”
“As an HIV negative gay men, I am often discriminated against. When I was single guys that were poz would not date me because they wanted bareback sex with other poz men because they had the same virus.”

I am left out of groups and services because I am not poz. I am sick to death of being made to feel like an outside because I don’t have HIV.”

There is a lot of stigma for HIV negative gay men but it’s never talked about because the focus is ALL on those who are poz.”
Stigma and HIV/AIDS

- Why is it important?
  - Increases HIV risk behavior
    - people less likely to disclose
  - Reduces willingness to be tested
  - Impedes access to prevention, care, treatment
  - Lowers adherence to treatment and prevention services
  - Adversely affects health outcomes
Treatment Cascade

HIV Treatment Cascade

- HIV-infected: 1,178
- HIV-diagnosed: 942 (80%)
- Linked to HIV care: 725 (77%)
- Retained in HIV care: 481 (66%)
- On ART: 427 (89%)
- Suppressed viral load (≤200 copies/mL): 328 (77%

*Numbers in thousands

Ref: MMWR 2011
DEFINING STIGMA
Stigma… (Goffman)

- Results from perceived violation of shared attitudes, beliefs, and values.
- Directed to those with an attribute that is deeply discrediting
- Reduces the bearer "from a whole and usual person to a tainted, discounted one."
- “Difference or deviance“ results in a "spoiled identity."
Felt Stigma

- Real or imagined fear of societal attitudes and potential discrimination
- Internalize negative perceptions of self
- Shame
- Survival strategy
- Self-imposed discrimination - a priori
Enacted Stigma

- Actual experience of **discrimination**
- Unfair treatment based, in the absence of anything objective, on someone belonging to a particular group
  - Excluded
  - Abandoned
  - Verbally abused or teased
  - Physically assaulted
  - Fired from work
  - Property taken away
  - Denied health services
Stigma is Dynamic

- Vulnerability varies along trajectory of HIV/AIDS progression

- Social context extremely important
  - poverty, racism, sexism
Compounded stigma

- Overlapping and reinforcing stigmatized conditions
  - Substance abuse/dependence
  - Disability
  - Co-occurring mental health concerns
  - Co-occurring infections (e.g., hepatitis)
  - Sex worker
  - Non-majority race/ethnicity
HIV
Reduce the number of people who become infected with HIV

Increase access to care and optimizing health outcomes for people living with HIV

Reduce HIV-related health disparities

Federal agencies have been charged with creating a coordinated federal response

www.aids.gov/federal-resources/policies/national-hiv-aids-strategy
Reducing New HIV Infections

Increasing Access to Care and Improving Health Outcomes for People Living with HIV

Reducing HIV-Related Disparities and Health Inequities

Graphic: Barbara Schedhtman, Midwest AIDS Training and Education Center
Transmission of HIV

- Injection Drug Use
- Mother to child transmission (MTCT)
- Occupational Exposure
- Sexual Contact
HIV Risk Continuum

No Risk

- Hugging/Dry kisses

Higher Risk

- Receptive anal intercourse
- Needle sharing/IDU
- Unprotected vaginal intercourse
- STIs increase risk

Alcohol and Drug Use
Prevention

Sexual Transmission
- Male and Female Condoms
- Dental Dams
- Surgical Gloves

Injection Drug Use Transmission
- Needle Exchange Programs

Abstinence

Treatment as Prevention
Bio-medical Interventions - Treatment as Prevention

HIV prevention methods that use antiretroviral treatments (bio-medical interventions) to decrease the chance of HIV transmission.

- Mother to child transmission (PMTCT)
- Post exposure prophylaxis (PEP)
- Pre exposure prophylaxis (PrEP)
- Begin antiretroviral treatment early on after HIV diagnosis.

- Routine HIV Testing
Assessing Risk Co-Factors: HIV, Mental Health, and Substance Use

- 26% of clients living with HIV experienced some form of anxiety disorder within a 12 month period.

- 60% of persons living with HIV/AIDS had either a major depression or dysthymia within a 12 month period.

- The use of substances increases risk for HIV and other sexually transmitted diseases due to its effect on decision-making and sexual risk taking behaviors.

- Of the 42% of patients who had been diagnosed with clinical depression, only 15% took their prescribed anti-depressants (SSRIs).

Sources: HRSA, APA, Clinical options.com, KFF
The link to trauma

- Sexual and/or physical abuse
- Domestic Violence
- Poverty
- Violence
- Diagnosed with a life-threatening illness
- Significant loss
- Others?

Substance use and recovery
HIV is a source of division in the gay community.
There is resentment in the community because HIV positive gay men receive more services and opportunities than HIV negative gay men, 30-39.
HIV Criminalization

- The Center for HIV Law and Policy
  - http://www.hivlawandpolicy.org/resourceCategories/view/2

- Seroproject.com
  - Includes many stories, information and even sample forms such as “HIV Disclosure Acknowledgment Statement”
Intrastatus Stigma

Among PLWHA

- Infected before/now
  - “In my day we didn’t know how one gets the virus..there’s no excuse for anyone getting infected now.”
- The “innocent” victims of AIDS
  - as opposed to…
- People that continue working as opposed to those on disability
The viral divide in the gay community

- “Gay men have known since the AIDS pandemic began that empowerment is the antidote to stigma.”
- “Stigma operates exactly like the deadly virus we claim to oppose. It infects pieces of us and then turns those factions against the rest, until the entire body [and community] is weakened and vulnerable.
- Mark King, POZ magazine
HIV is a source of division in the gay community
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Positive = Disagree
Resentment about services for HIV positive (50s)
Do you feel that phrases like "Clean Only" or "UB2" or "D/D Free" increase stigma? 30-39

- 40.0% (2) - Disagree
- 40.0% (2) - Strongly Agree
- 20.0% (1) - Agree

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly Agree
- No opinion/ don't know
Stigmatizing phrases (50s)

Do you feel that phrases like "Clean Only" or "UB2" or "D/D Free" increase stigma?

Left: Do you feel that phrases like "Clean Only" or "UB2" or "D/D Free" increase stigma? (negative)
- 50.0% (2)
- 25.0% (1)
- 25.0% (1)

Right: Do you feel that phrases like "Clean Only" or "UB2" or "D/D Free" increase stigma? (positive)
- 53.3% (7)
- 22.1% (3)
- 7.7% (1)
Stigmatizing Phrases (all ages)
Sex partners are same HIV status (30s)

My sex partners are typically of the same HIV status as me. 30-39

Positive = Strongly Disagree
Sex partners are same HIV status (50s)
Measures of Stigma

- Mostly for research
- Few tested and utilized for surveillance
- United States and international
- Have 2 perspectives:
  - “stigmatizers” (general public, specific groups, or healthcare workers)
  - "stigmatized"
Available Indicators

- Social distance
- Support for coercive measures
- Willingness to interact with PLWHA
- Emotional reactions to PLWHA
International Center for Research on Women

STRIVE: Addressing the Structural Drivers of HIV

Strategic Framework and Implementation Guidelines for Reducing HIV-related Stigma in India

Reducing HIV-Related HIV risk in Kabila, Namibia
Measuring HIV Stigma and Discrimination

(Technical Brief, July 2012)

http://strive.lshtm.ac.uk/sites/strive.lshtm.ac.uk/files/STRIVE_stigma%20brief-A3.pdf

Consortium: Strive (London School of Hygiene and Tropical Medicine), ICRW, UKAid

Illustrative questions by domain
Example from Strive Technical Brief

- **Domain: Social Judgment**
  - **General Population**
    - Do you agree or disagree with this statement:
      
      "I would be ashamed if someone in my family had HIV"
  
  - **Healthcare Workers**
    - Likert scale (strongly disagree, disagree, etc): "People living with HIV could have avoided HIV if they wanted to."
Example from Strive Technical Brief

- (Domain: Social Judgment)
- People Living with HIV
  - Do you agree or disagree with the following: “People think that having HIV is shameful and they should not be associated with me.”
Interventions

- Socio-Cognitive interventions
- Mass media
- Structural approaches
  - Role of power
THESTIGMAKEYPROJECT

ELEPHANT REMOVAL REQUIRED.

YOU DON'T HAVE TO WHISPER.
IT'S OKAY TO TALK ABOUT HIV.
YOU JUST MIGHT LEARN SOMETHING.
The Stigma Project

HIV Disclosure Etiquette

Your friend just told you they have HIV. Here are a few suggestions on how to properly respond.

Avoid

“How long do you have?”

“How did you get it?”

“Who gave it to you?”

“Why am I not surprised?”

“I’m not gonna get it am I?”

Say

“You’re not alone.”

“Have you started treatment yet?”

“I’m here for you.”

“Have you found a good doctor?”

“I appreciate you telling me that.”

Asking questions about HIV is important to learning & understanding it. But remember there’s a time & place, and right now your friend needs you to be strong & supportive, not offensive.

The Stigma Project
The Stigma Project

Dating Profiles & HIV

Language you should adjust if you want to avoid confusion or reduce stigma around HIV with your potential dating or sex partners.

Avoid

“Clean”
When referring to HIV, implies those who are positive are dirty or unclean. “Clean” also causes a lack of clarity within the conversation because the term has many different connotations.

“Drug & Disease Free” or “DDF”
Suggests the two are mutually inclusive and that people with HIV also use drugs.

“Neg Only”
Discourages people from getting tested and diminishes the esteem of those who are positive. It also ends the conversation before it should begin.

Say

“Neg, Tested on [Insert Date]”
Keep it updated. If sexually active you should get tested every 3 months. If you feel like your testing date should remain private, at least provide a general time frame so the potential partner can properly assess their risk.

It’s easy to forget about the people affected by our word choices when we never see them face-to-face. We hide behind our screens and pay no mind to how our language may offend, degrade, or hurt an entire community.
Addresses younger population
Information and video personal accounts
  Young + Positive Ambassadors
Twitter feed
Role of PLWHA

- **GIPA (Greater Involvement of People Living with HIV/AIDS)**
  - Paris AIDS Summit 1994
  - Adopted as UN principle

- The People Living with HIV Stigma Index Tool
  (www.stigmaindex.org)
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