

Introduction to HIV Stigma

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Goals

- (1) What is stigma?
- (2) What are the consequences of stigma?
- (3) What do we do to eradicate it?

Erving Goffman

Stigma: Notes on the Management of Spoiled Identity (1963)

Definition:

an attribute that is deeply discrediting, that reduces the individual's status or worth in the view of society, and labels the person as different or deviant

- > discredited
- > discreditable

Stigma is a social process

Stigma happens when four things occur:

- Individuals differentiate and label the variation
- Prevailing beliefs tie adverse attributes to those labeled as different
- Labeled groups are further distinguished as “them” vs. “us”
- Labeled persons experience status loss and discrimination, causing inequality in life chances (income, education, mental health, health and health care)

Bruce G. Link and Jo C. Phelan , "Conceptualizing Stigma", *Annual Review of Sociology*, 2001, p.363

Stigma is about power

- Those in the mainstream of society have the social, economic, and political power to implement these four steps: to identify the differences, to attribute negative attributes to them, to separate the labeled into a different group (them) and to execute the disapproval, rejection and discrimination.
- *Labeling and discrimination exist because a power situation created and permitted it to persist.*

Not all illnesses are stigmatized

An illness is more likely to be stigmatized when...

- 1) perceived to be the person's responsibility, especially if those behaviors are themselves disapproved (sex, IV drug use)
- 2) fatal, degenerative, permanent – it is a reminder of our vulnerability
- 3) contagious or believed to put people at risk
- 4) physically changes people's appearance or stamina

Which people with HIV are stigmatized?

- HIV stigma is universal, found worldwide
- *However*, unpopular groups are disproportionately affected by stigma. Pre-existing prejudices and discrimination feed upon differences and result in labeling and stigma.
- Targets of HIV stigma reflect this fact
 - > HIV transmission routes (transfusion vs. shared needles)
 - > Typically women more than men

Who does the stigmatizing?

- All of us
- Some less than others:
 - Younger, better educated
 - Personally knowing someone with HIV/AIDS
 - Positive attitudes towards LGBT
 - Accurate knowledge about HIV transmission

Consequences

- Forms of stigma
 - > Enacted Stigma
 - > Perceived Stigma
 - > Internalized Stigma
- Consequences
 - > Prevention
 - > PLWA
 - > Their family and friends
 - > Public Policy

The Experience of HIV Stigma

“Enacted Stigma”

Ostracism (“social distance”)

- 37% of HIV+ respondents worldwide felt strong feelings of isolation
- 38% felt judged by others
- Half had met someone who was afraid to have casual contact
- 42% had “strong concerns” about disclosure



Enacted Stigma

Discrimination

- Denial of rights, resources or services
 - Evicted from their homes
 - Denied rental housing
 - Fired from or refused employment
- Violence and murder
 - AIDS-related murders documented in Brazil, Colombia, Ethiopia, India, South Africa and Thailand

**ALL
PEOPLE WITH AIDS
ARE
INNOCENT**



Credit: The New York public library

SPENDING AIDS ACTION '96. More days of unaffordable AIDS-related activities & programs.

Time To Act

Enacted Stigma

Delayed or poor quality health care

- Doctors refuse to care for HIV+ individuals
- HIV+ individuals are denied health insurance
- Access to HIV/AIDS medications limited/denied
- Lack of confidentiality
- Tested without consent

Enacted Stigma

Limited access to opportunities

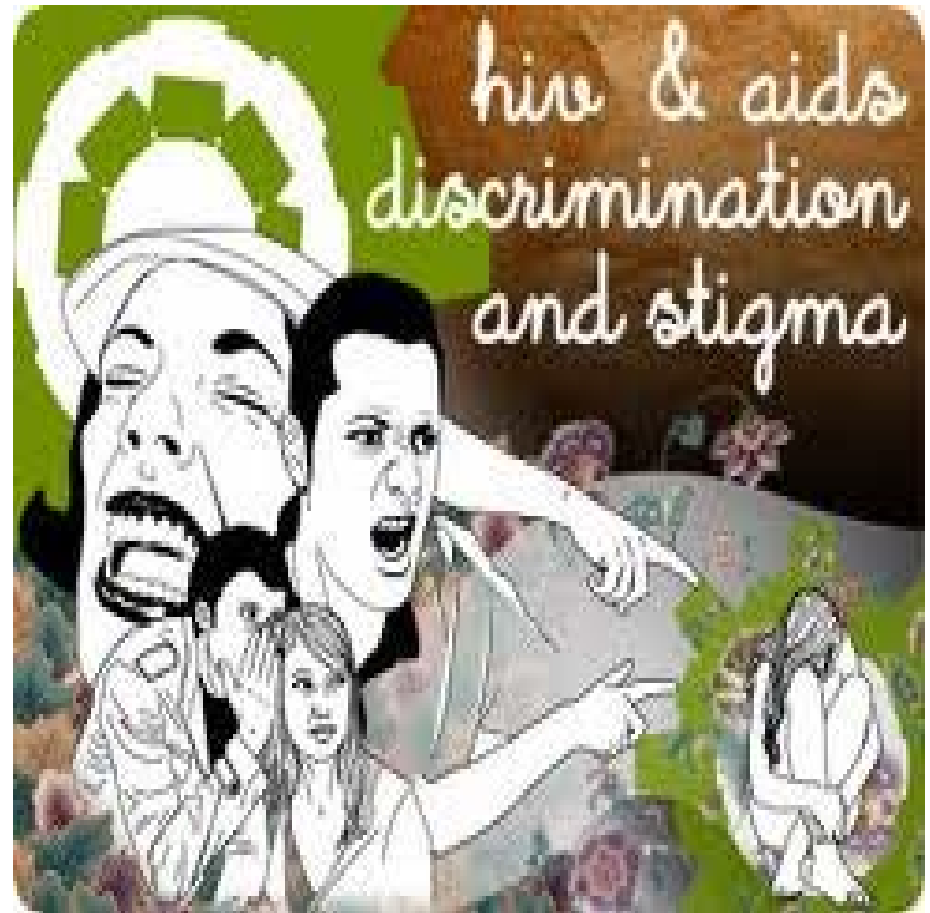
- Travel
 - 60 countries or areas restrict entry, stay or residence based on HIV positive status
 - Five countries require a declaration of HIV status to enter
 - 22 countries deport foreigners based on HIV status alone
- Refusal to enlist volunteers into the military, or discharge of HIV+ military members
- Schools fail to protect confidentiality of HIV+ students, bullying, teasing rejection

Perceived Stigma

- Imagined fear of social ostracism
- Fear of discrimination
- Actions
 - > Refuse testing
 - > Refuse condom use
 - > Refuse to disclose HIV status

Internalized Stigma

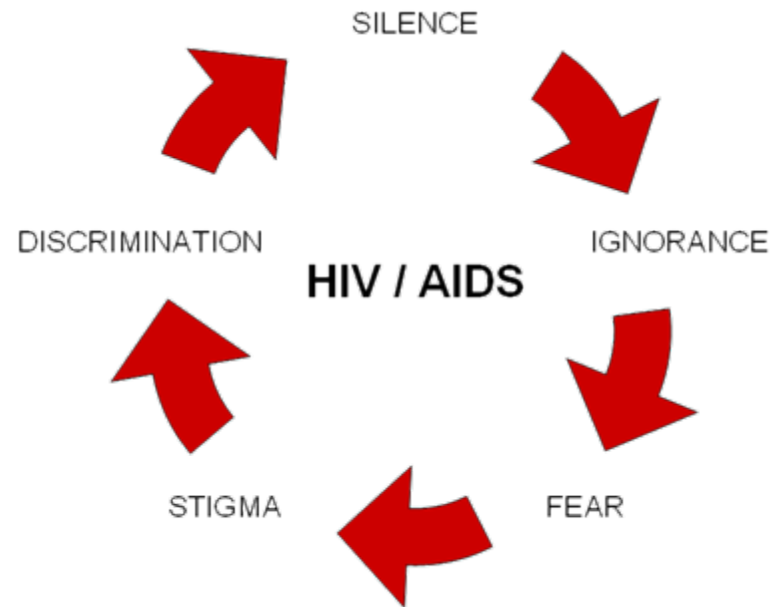
- Accepting as true about oneself the negative stereotypes the society holds about HIV/AIDS and PLWA (labeling theory)
- Self blame, loathing, depression, low self-esteem
- Guilt over consequences for others (e.g. transmission, burden)
- *However*, many people with HIV have high self-esteem, perform at high levels



Consequences of Stigma --For Prevention

Perceived stigma is the main reason that people do not get tested or obtain treatment

- More HIV+ people go undiagnosed, and continue to infect others
- HIV is diagnosed late, treatment is less effective, and there is early death
- Pregnant women refuse the test, resulting in transmission to their children even where treatment is free



Consequences of AIDS Stigma

-- For PLWA

- Loss of income or work
- Loss of marriage and childbearing options
- Poor health care
- Rejection by family and unavailable caregivers
- Feelings of rejection, guilt and worthlessness

Consequences of AIDS Stigma

-- For PLHA

- Do not disclose to others out of fear of rejection
- Are isolated when support is needed the most
- Constant anxiety about disclosure
- Lying to family and friends causes suffering
- Can lose one's job when productivity is compromised
- Perpetuates stigma – no opportunity to challenge the attitudes that require secrecy in the first place

Consequences of Stigma

-- For Family, Friends, Providers

- “Courtesy Stigma” from HIV/AIDS that people “around” the PLWA experience
 - WHO?
 - Families
 - Caregivers
 - Service providers, social activists, volunteers
 - WHAT?
 - Ostracism, discrimination
 - Lack of support
 - Fewer willing to help

Consequences of HIV Stigma

-- For Public Policy

- Policy is made by people affected by the same stigma as society
- Response to the epidemic was slow and inadequate
- Media coverage was limited, then inflammatory
- Resources spent correcting inaccuracy rather than fighting the epidemic
- Failure to implement effective policies
 - Needle exchange
 - Condom distribution to young people
 - Honest explicit sexuality education

What to Do?

Promising ways to reduce HIV/AIDS stigma

Three general approaches:

(1) statutes and regulations

(2) policy

(3) programs and services



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(1) Statutory and Regulatory

- Confidentiality of HIV-related information protected under State laws and the U.S. Constitution
- Discrimination unlawful : Americans with Disabilities Act, 1990
- HIV infection defined as a disability under Federal and State laws protecting the disabled from discrimination in employment, housing, government services, hotels, schools, and medical offices.
- These are not universal worldwide or enforced
- UN Secretary General Ban Ki-moon in 2008 called for more enlightened laws and public policy

(2) Public Health Policy: “HIV exceptionalism”

- HIV exempted from traditional public health practices such as contact tracing and partner notification.
- AIDS is a reportable disease in all 50 States, but requirements for reporting vary
- Support for HIV exceptionalism is waning as effective therapy became available and HIV stigma has declined
- Call for integrating HIV testing and treatment into routine medical care

(3) Stigma Programs and Services

- Horizons (Population Council) identified 21 interventions that explicitly aim to decrease AIDS stigma in developed and developing countries
- All were evaluated
- Target PLWA and perpetrators of stigma
- Programs include
 1. Education
 2. Contact with affected groups
 3. Coping skills acquisition
 4. Counseling approaches

Stigma Interventions

- Goals
 - > Increase tolerance of PLWA
 - > Increase empathy and altruism
 - > Decrease anxiety and fear of contagion
- Targets
 - > Health care workers
 - > Community members, youth, students
 - > PLWA
 - > Entire communities
- Findings
 - > Proven to reduce (not eliminate) stigma
 - > Doing more than just education is more effective

What Needs to be Done?

- Surveillance: document and monitor stigma on a routine basis using stigma scales with strong psychometrics
- Intervention: develop interventions to reduce AIDS stigma and rigorously evaluate them
- Translation: test proven interventions in various settings and populations and scale up

What to do?

- **Challenge those who stigmatize**
 - > Education
 - > Legislation against discrimination
 - > Mobilization of the community in anti-stigma efforts
- **Challenge internalized stigma**
 - > Sex workers in Sonagachi, a red light district in India challenged internalized stigma
 - Respect for taking care of their families
 - Respect as workers with rights
 - Provided evidence that sex workers can achieve valued aims, and are respected by others

Who must act?

- The Wise -- their special situation provided a measure of acceptance, a measure of “courtesy membership in the clan.”
- Who are The Wise?



 **KNOW, PREVENT, CARE, CURE.**

MEET AN EXTRAORDINARY COALITION OF AIDS ACTIVISTS WHO HAVE COME TOGETHER TO RAISE VITAL AWARENESS AND ADDRESS THE DESTRUCTIVE STIGMA ASSOCIATED WITH HIV/AIDS.

Stigma is the Root Cause of the AIDS Pandemic

“Stigma remains the single most important barrier to public action....It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world.”
UN Secretary-General Ban Ki-moon

Ban Ki-moon op ed (2008, 6th August), The Stigma Factor *The Washington Times*

INTERNATIONAL CONFERENCE ON **STIGMA**

...the attitude that spreads HIV



WORLD AIDS DAY
DECEMBER 1, 2010
8:30AM - 5:00PM

HOWARD UNIVERSITY
Cromton Auditorium & Blackburn Center
2400 6th Street NW Washington, DC 20059

FREE & OPEN TO THE PUBLIC

Stigma prevents individuals with HIV from getting tested, seeking care, disclosing their diagnosis, taking their medication and follow-up. Fear of losing relationships prevents individuals from disclosing their diagnosis.

Join us in our fight to end stigma! **Become a partner.**

To register or learn more attend this free conference, call (202) 845-7362 or visit

www.whocanyoutell.com

