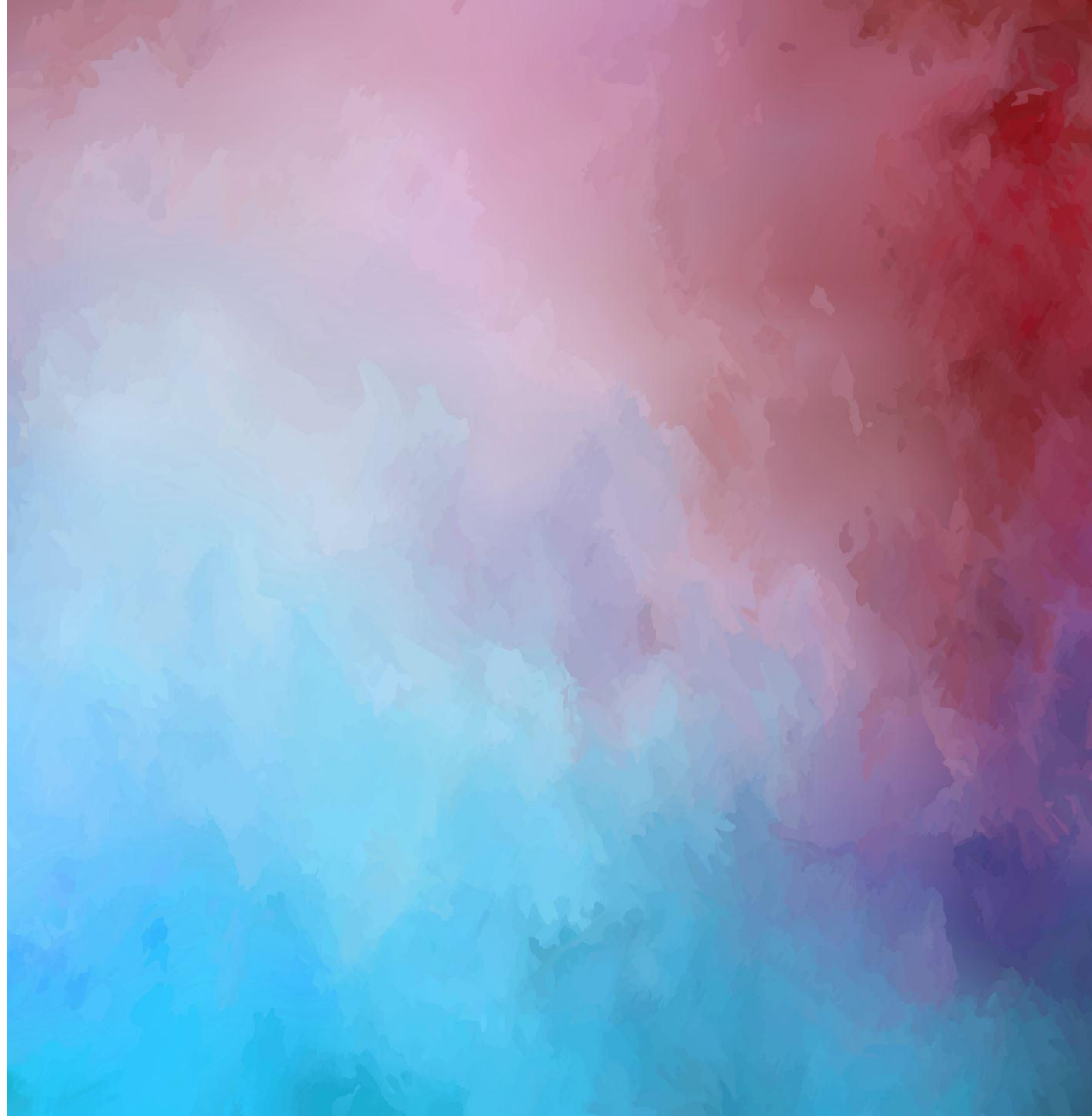




HIV/AIDS, SHAME AND STIGMA

By David Harvey, LCSW,
MSS, MA



Objectives

Overview of Shame, as well Shame in Relation to People Living w/ HIV/AIDS

Three-part periodization that underscores generational differences in shame response connected with HIV/AIDS

Primary Experience of Shame

- “The shame response represents **the failure of the smile of contact**, a reaction to the loss of the other, indicating social isolation and the need for relief from that condition.”
- **Franz Basch**



Shame, Stigma and HIV/AIDS

- HIV inflames pre-existing shame dramatically
- Undetectable equals Untransmittable. However, 41% of people believe all HIV positive people can transmit the virus (2019)
- Advances in reducing stigma with HIV have not kept pace with the rapid advances in HIV treatment. Hence, HIV/AIDS and its distressing correlation with psychopathology.
- Stigma is a socially constructed phenomenon



3-Part Periodization of MSM Communities in relation to HIV/AIDS

- 1. Older Group (born before 1971) Direct community experience of HIV/AIDS during the Crisis Era (1981 – 1996)
- 2. Middle Group (born between 1972 and 1988) Indirect exposure/experience with HIV/AIDS, during the Crisis Era through sensationalized and shame-based discourses and representations (Media)
- 3. Younger Group (born after 1988) Minimal to zero experience/exposure to HIV/AIDS during the Crisis



STIGMA DEFINED

- Derived from Greek meaning “tattoo or stain”
- Unruly enslaved People and criminals were branded, oftentimes on the forehead
- The mark would signify disgrace

- Irving Goffman (1963)
 - Links stigma to social difference of a less desirable kind, “the extreme a person who is quite bad, or dangerous or weak. [They] are reduced from a whole person to a tainted, discounted one.”
 - Discredited vs Discreditable
 - Passing
 - Mixed Encounters
 - Courtesy Stigma
 - 1. Abnormalities of the body. 2. “Blemishes of character perceived as weak will, domineers passions, treacherous beliefs and dishonest inferred from a known record of mental illness, addiction, imprisonment, unemployment.”




STIGMA DEFINED CONTINUED

Edward Jones (1984)

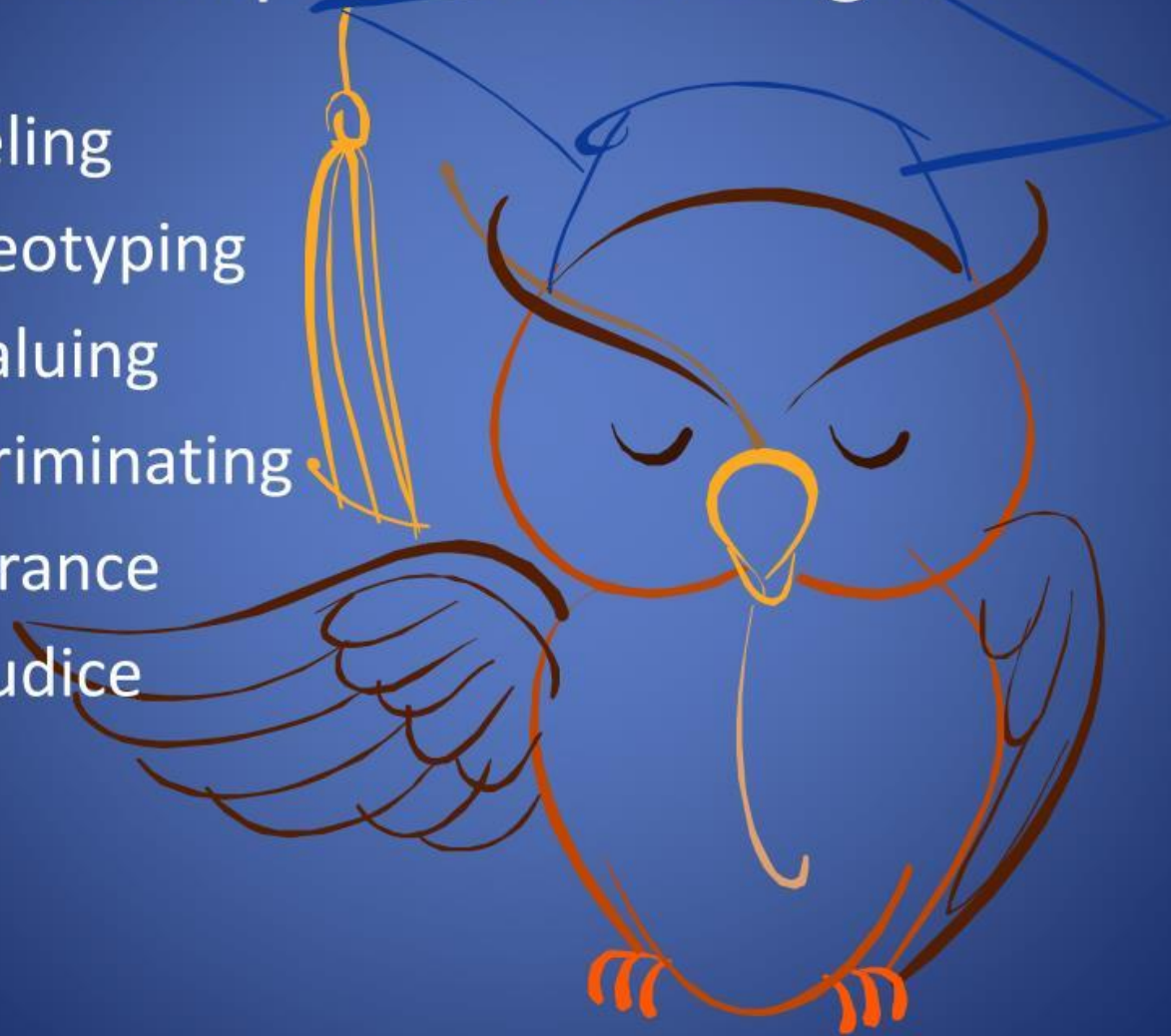
- Environmental and Historical Context of Stigma
- Blame
- Danger

Scambler and Hopkins (1986):

- Felt, Internalized or Self-Stigma
 - Fear of Enacted Stigma
- 

Components of Stigma

- ❑ Labeling
- ❑ Stereotyping
- ❑ Devaluing
- ❑ Discriminating
- ❑ Ignorance
- ❑ Prejudice





Effects of Stigma

Decreased Access

- Employment
- Housing
- Treatment
- Interpersonal Relationships

Negative Self-Image

- Mental Health Disorders, including addiction
- Minority Stress
- Avoidance of protective factors

Theories on Addiction

- A Moral Failing
- A Spiritual Deficient
- A Character Disorder
- Poor Willpower
- **The contemporary consensus is that addiction is a biopsychosocial disorder that is preventable and treatable. Moreover, most people do recovery**



Contributing factors to HIV Stigma in Medical Providers

Lack of awareness of people in with HIV/AIDS

Burnout

Poor role models and leadership

Insufficient Education



What are some stigmatizing beliefs about people with HIV?

Discussion

HIV #LanguageMatters: Using preferred language to address stigma



Created for & by People Living with HIV

Acknowledgements:
 thewellproject



Stigmatizing	Preferred
HIV infected person	Person living with HIV, PLHIV. Do not use "infected" when referring to a person. Use <i>People First Language</i> , which emphasizes the person, not their diagnosis
HIV or AIDS patient, AIDS or HIV carrier	
Positives or HIVers	
Died of AIDS, to die of AIDS	Died of AIDS-related illness, Died of AIDS-related complications or end stage HIV
AIDS virus	HIV (AIDS is a diagnosis not a virus - it cannot be transmitted)
Full-blown AIDS	There is no medical definition for this phrase - simply use the term AIDS, or Stage 3 HIV.
HIV virus	This is redundant; use HIV.
Zero new infections	Zero new HIV acquisitions/transmissions
HIV infections	HIV transmissions, diagnosed with HIV, PLHIV
HIV infected	living with/diagnosed with HIV, contracted/acquired HIV
Number of infections	Number diagnosed with HIV/number of HIV acquisitions
Became infected	Contracted, acquired, diagnosed with
HIV-exposed infant	Infant exposed to HIV
Serodiscordant couple	Serodifferent, magnetic, or mixed status couple
Mother to child transmission	Vertical transmission/perinatal transmission
Victim, Innocent Victim, Sufferer, contaminated, infected	Person living with HIV, survivor, warrior (Do not use "infected" when referring to a person)
AIDS orphans	Children orphaned by loss of parents/guardians who died of AIDS related complications
AIDS test	HIV test (AIDS is a diagnosis, there is not an AIDS test)
To catch AIDS, To contract AIDS, Transmit AIDS, To catch HIV	An AIDS diagnosis, developed AIDS, to contract HIV (AIDS is a diagnosis, which cannot be passed from one person to the next)
Compliant	Adherent
Prostitute or prostitution	Sex worker, sale of sexual services, transactional sex
Promiscuous	This is a value judgment and should be avoided instead use "having multiple partners"
Unprotected sex	Condomless sex with PrEP, Condomless sex without PrEP, sex not protected by condoms, sex not protected by antiretroviral prevention methods
Death Sentence, Fatal condition or life-threatening condition	A serious health issue, chronic health condition or manageable health for people who have access to care and treatment
"Tainted" blood; "dirty" needles	Blood containing HIV; shared needles, shared syringes
Clean, as in "I am clean are you?"	Referring to yourself or others as being "clean" suggests that those living with HIV are dirty. Avoid!
"a drug that prevents HIV infection"	a drug that prevents the transmission of HIV
End HIV, End AIDS	End HIV transmission, Be specific: are we ending HIV or AIDS?



This is a "living document" - suggestions and new ideas are welcome. This is our language!

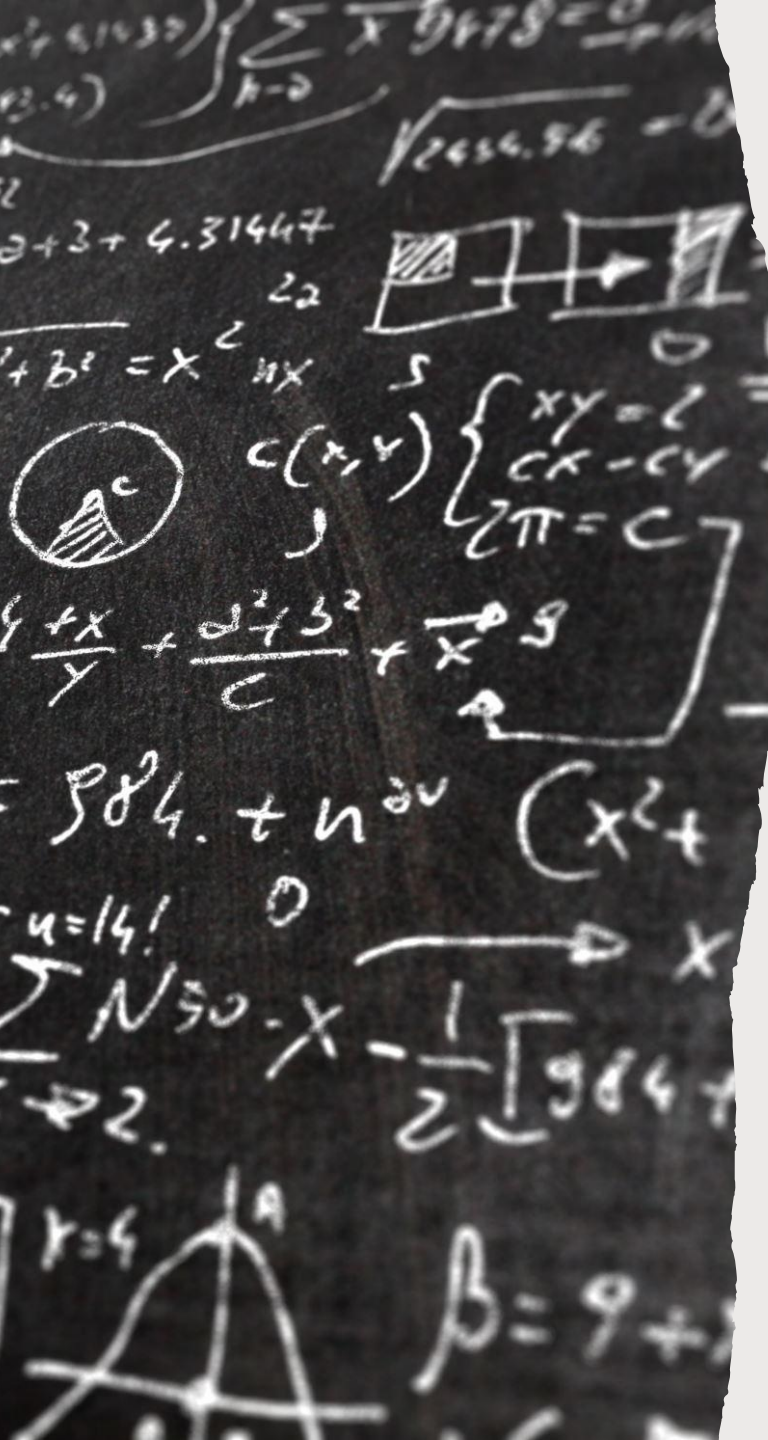
For Reprints: Contact Vickie Lynn vlynn@health.usf.edu or Valerie Wajsborn v.wajsborn@hivmail.com

Reasons for Stigmatizing Behavior

- Gaining or Maintaining Power Over Another Person
- Fear of Difference
- Ignorance: People aren't aware of modern science and evolving cultural attitudes
- Purposeful: People take out of their frustrations and past traumas on others
- Poor Workplace Culture
- Lack of Clear Rules or Lack of Enforcement of these Rules

Tactics for Confronting Stigma

- Humor: Humor can dispel some of the tension that comes from confrontation. It can also disarm a person. If humor feels natural to you and is a strength, embrace it. If it isn't, perhaps steer clear of this strategy
- Self-Talk: Practice what you would say to prepare yourself. Role play possible reactions, imagining both positive and negative reactions
- Self-Assertion: Act on your ethics and values and let these guide you. Be forthright and use "I" language, i.e. "I felt stigmatized when you _____. Can you please stop?" "I noticed or imagined this person felt stigma when _____? Where you aware of that?"
- Recognition of Risk: If you believe it is unsafe to confront the stigmatizer, prioritize your personal safety as well that of the target of stigma (if other than yourself). It is not always possible or safe to intervene.



Guidelines of Communication

- Be knowledgeable. Misinformation or disinformation will undermine your intentions. Be discerning in your resources.
- Work on your messaging. Cultivate concise and impactful language. Don't be afraid to draw on examples of stigma and its impact.
- Listen
- Be mindful of alternative opinions. Don't go to great pains to contradict others. Simply present your own message and don't shy away from repetition to emphasize points.
- "I don't know" is the best response when confronted with a question you cannot adequately address. If possible, direct your interlocuter to persons or resources that may be able to provide an answer.



Discussion

Dialogue around a case study/example

Conclusion and Main Points

- Stigma is a major factor impacting overcomes and the overall well-being of people with SUDs
- Unfortunately, Health Care Professionals can provide stigmatizing care
- Treat patients with HIV with dignity and empathy
- Identify stigmatizing beliefs and behaviors and address them respectfully



Bibliography

- Basch, M. F. (1976). The concept of affect: A re-examination. *Journal of the American Psychoanalytic association*, 24(4), 759-777.
- Odets, W. (2019). *Out of the shadows: Reimagining gay men's lives*. Farrar, Straus and Giroux.
- Alexander, I. E. (1995). *Shame and its sisters: A Silvan Tomkins reader*. Duke University Press.
- Sedgwick, E. K. (2009). Shame, Theatricality, and Queer Performativity: Henry James's *The Art of the Novel*." *Gay Shame*. eds david m. Halperin and valerie traub.
- [Almost half of Brits would feel uncomfortable kissing someone with HIV | Terrence Higgins Trust \(tht.org.uk\)](https://www.tht.org.uk/news/2019/06/19/almost-half-of-brits-would-feel-uncomfortable-kissing-someone-with-hiv)