AIDS United: Stamp Out Stigma
Challenging HIV and AIDS Discrimination
Trainer Today:

LaTrischa Miles

STAMP OUT STIGMA
Challenging HIV and AIDS discrimination
Objectives

By the end of this presentation, you will be able to:

• Objectives:
  – Define stigma and its impact on HIV prevention, treatment and care.
  – Explain the role of stigmatizing versus empowering People First Language.
  – Demonstrate through case studies the use of empowering self-talk.
What is Stigma?

• “Negative feelings, beliefs and behaviors directed toward an individual or group due to a particular label or characteristic.”

• “Disqualification from full social acceptance”

• “by definition, or course, we believe the person with a stigma is not quite human. On this assumption, we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances” (Goffman, 1963)
HIV and AIDS Related Stigma

HIV/AIDS related stigma refers to prejudice, discounting, discrediting and discrimination directed at persons perceived to have AIDS or HIV, as well as their partners, friends, families and communities.*

HIV and AIDS Related Stigma

HIV and AIDS stigma is manifested through populations that include:

- Individuals with HIV/AIDS
- Individuals incarcerated or formerly incarcerated, and
- Individuals challenged with substance use

## HIV and AIDS Related Stigma

HIV/AIDS stigma is experienced at the individual, organization and societal level:

<table>
<thead>
<tr>
<th>Individual Level</th>
<th>Organization/Institutional Level</th>
<th>Societal Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Ostracism, rejection and avoidance</td>
<td>• Name or organization</td>
<td>• Laws, policies and/or regulations</td>
</tr>
<tr>
<td>• Prejudice</td>
<td>• Business cards</td>
<td>• Social conditions of persons living with HIV/AIDS</td>
</tr>
<tr>
<td>• Mandatory HIV testing without prior informed consent or confidentiality protections</td>
<td>• Provider language</td>
<td>• Discrimination in employment, housing, military service, access to health services, social and community programs</td>
</tr>
<tr>
<td>• Quarantine of persons who are HIV infected</td>
<td>• Environment</td>
<td></td>
</tr>
<tr>
<td>• Violence</td>
<td>• POZ Magazines</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Educational materials</td>
<td></td>
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</tbody>
</table>

HIV and AIDS Related Stigma
Global

Stigma is a Global problem expressed in a variety of ways, including:

• Access to appropriate treatment and care is a fundamental human right, discrimination prevents individuals from getting tested and seeking or adhering to treatment and care due to stigma.

INTERNAL STIGMA
INTERNAL STIGMA DEFINED

Felt stigma (internal stigma or self-stigmatization) refers to the shame and expectation of discrimination that prevents people from talking about their experiences and stops them seeking help.
INTERNAL STIGMA

Internal Stigma and Shame

- **SHAME = I am bad**
  - I am not worthy

- **Amplifiers of SHAME**
  - Silence
  - Secrecy
  - Judgment
Strategies

• Media
• Providers
• People Living with HIV
INTERNAL STIGMA - STRATEGIES

Strategies

• Self acceptance
• Self care
STIGMATIZING SELF-TALK vs EMPOWERING SELF-TALK

Stigmatizing self talk

I’m infected with HIV.

It’s my fault I got infected; injecting drugs.

Incarcerated=criminal

“Gay” people of color

Empowering self talk

I am a person living with HIV.

No one deserves HIV; HIV is not a punishment.

Being incarcerated does not define you as a person nor brand you as a criminal.

Same gender loving.
STIGMATIZING SELF-TALK vs EMPOWERING SELF-TALK

Stigmatizing self-talk

HIV infected mother.
She’s an addict.
I work with felons.
AIDS virus
Arthur Ashe died of AIDS February of 1993.
The weather is Schizophrenic.

Empowering self-talk

(???)
(???)
(???)
(???)
(???)
(???)
STIGMA IMPACTS: HIV Prevention, Treatment and Care

- Counseling and Testing
- Individual and Access to Care
- Disclosure of Status
- Health Disparities
STIGMA IMPACTS: HIV Prevention, Treatment and Care

Stigma → Testing → People Living With HIV know status → Disclosure & Quality of Life → New Infections

Stigma → Testing → People Living With HIV know status → Disclosure & Quality of Life → New Infections
Self-Talk Empowering Messaging
People First Language

• Rather than use labels to define individuals with a health issue, it is more appropriate to use terminology, which describes individuals as being diagnosed with an illness or disorder.

• For Example-

  mentally ill people (instead use) - persons with a mental health challenge
## Incorrect Terminology*

<table>
<thead>
<tr>
<th>Incorrect Terminology</th>
<th>Correct Terminology</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS virus</td>
<td>HIV</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>HIV</td>
</tr>
<tr>
<td>HIV/AIDS (only when referring to AIDS)</td>
<td>HIV</td>
</tr>
<tr>
<td>HIV and AIDS</td>
<td>AIDS (only when referring to AIDS)</td>
</tr>
<tr>
<td>Promiscuous</td>
<td>This is a value judgment and should be avoided</td>
</tr>
<tr>
<td>Risk group</td>
<td>Risk</td>
</tr>
<tr>
<td>Risky sex – Unprotected sex</td>
<td>Be specific on what you are saying. Condomless sex with PrEP or without PrEP</td>
</tr>
</tbody>
</table>

*UNAIDS Preferred Language for Reporting on HIV and AIDS
# Insensitive Language*

*UNAIDS Preferred Language for Reporting on HIV and AIDS

<table>
<thead>
<tr>
<th>Stigmatizing</th>
<th>Preferred</th>
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<tbody>
<tr>
<td>PLHA or PLWHA</td>
<td>People living with HIV or Person with HIV</td>
</tr>
<tr>
<td>HIV patient, AIDS patient</td>
<td>Person living with HIV</td>
</tr>
<tr>
<td>Positives or HIVers</td>
<td>People living with HIV</td>
</tr>
<tr>
<td>AIDS/ HIV carrier</td>
<td>Person living with HIV</td>
</tr>
<tr>
<td>Died of AIDS, to die of AIDS</td>
<td>Died of AIDS-related illness or AIDS-related complication or end stage HIV</td>
</tr>
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</table>
## Insensitive Language*

<table>
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<th>Preferred</th>
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</thead>
<tbody>
<tr>
<td>Victim</td>
<td>Person living with HIV</td>
</tr>
<tr>
<td>Contaminated</td>
<td>Do not use</td>
</tr>
<tr>
<td>Innocent (victim)</td>
<td>Do not use</td>
</tr>
<tr>
<td>AIDS orphans</td>
<td>Children orphaned by loss of parents or guardians who died of AIDS related complications</td>
</tr>
</tbody>
</table>
Using People First Language
Using People First Language Examples

• Women are most likely to be infected with HIV through heterosexual contact.
• Women are most likely to contract or acquire HIV through heterosexual contact.

• Cardiovascular disease has become a major concern among HIV-infected individuals.
• Cardiovascular disease has become a major concern among people living with HIV.

• Mentally ill people are often diagnosed with AIDS virus * when proper medical care is ignored.
• Persons with a mental health challenge are often diagnosed with AIDS when proper care is not provided or ignored.

*AIDS is not a virus; it’s a syndrome and a result of inadequate care or treatment.
HIV is the virus.
# People First Language

<table>
<thead>
<tr>
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<tr>
<td>Mentally ill people</td>
<td>Person with a mental health challenges</td>
</tr>
<tr>
<td>HIV infected</td>
<td>Person living with HIV</td>
</tr>
<tr>
<td>Mother to child transmission</td>
<td>Vertical transmission</td>
</tr>
<tr>
<td>HIV infected mother</td>
<td>Mother living with HIV</td>
</tr>
<tr>
<td>HIV infected baby</td>
<td>Baby living with HIV</td>
</tr>
</tbody>
</table>
Case Scenario: Stigmatizing versus Empowering People First Language

Justine, a young African American woman age 21, was diagnosed with HIV when she was 18 years old. At diagnosis, she had a CD4 of 350 and a viral load of 3,000.

While her mother had always brought her to doctors appointments, she secretly told a clinic staff member that she was forbidden to talk about HIV in the home to family or friends. She said that she felt dirty and ashamed because her mother was a leader in the community, she came from a good family.

“I can’t let the secret out,” she told the clinic staff member before she left for college. The staff member has not seen Justine but she’s home for summer break and she called the clinic because she’s feeling ill, has thrush, and has had the flu.

• What are some concerns for the client’s care?
• What language is stigmatizing?
Case Scenario: Stigmatizing versus Empowering People First Language

Place – Clinic Huddle
You are a clinic staff member working with a client, Felicia, who has received HIV care at your clinic for many years, but recently started Medication-Assisted Treatment for her opioid use. Felicia has used heroin for over 10 years, but she has recently been arrested for drug possession and her partner has threaten to leave her. Felicia entered treatment herself after her release from jail and says she’s serious about decreasing her drug use.

The nurse says: I’ve talked to Felicia so many times about her opioid use. I’m not surprised that she was arrested. I’m really tired of setting up treatment schedules and doing paperwork. She’s only been out of jail for a few weeks and she’s already on the wrong track. I think she’s probably still having risky sex and shooting heroin. A seasoned clinic volunteer in the huddle says: I agree with you because addicts don’t always take life serious especially when they get out of jail; I would be over it too.

• How should the staff member respond in the huddle?
• What are some concerns for the client’s care?
• What language is stigmatizing?
What Can We Do?

• Committing yourself and/or your organization to using preferred, less stigmatizing language

• *Use People First Language when referring to people living with a medical condition.*

• Talk with colleagues and friends and educate others! Encourage use of People First Language and other preferred terminology.

• Change organizational documents and educational materials to reflect preferred language when possible.

• Create future organizational documents and educational materials that reflect preferred language.

• Include people with diverse backgrounds disproportionately impacted by HIV, such as MSM of color, transgender people, women, and youth in the creation of organizational documents and materials. This will help ensure that language is culturally appropriate beyond just the issue of HIV.
References

- Valerie Wojciechowicz and Vickie Lynn, MSW, MPH, HIV and Language Positive Women’s Network USA: [www.pwn-usa.org](http://www.pwn-usa.org)
- People First Language: [www.disabilityisnatural.com/people-first-language.html](http://www.disabilityisnatural.com/people-first-language.html)
- People Living with HIV Stigma Index – User Guide: [www.stigmaindex.org/about-index](http://www.stigmaindex.org/about-index)
- HIV #LanguageMatters: Addressing Stigma by Using ... - HIV
Questions?