Eliminating Stigma from the Language of HIV Communications

Presenters:
Vickie Lynn, MSW, MPH
Valerie Wojciechowicz
Olivia Ford (Introductions / Moderation)

February 3, 2015
WELCOME!
Moderator: Olivia Ford

As Communications Director at PWN-USA, **Olivia Ford** coordinates the organization's communications strategy while working with PWN-USA's members to build their capacity to engage in media and communications work. She previously worked at TheBody.com, a comprehensive Web-based HIV resource. There she conducted interviews and developed materials on such topics as the intersections of trauma, gender-based violence and HIV; health care access in transgender communities; the rollout of PrEP for US women; criminalization and stigma; as well as many aspects of becoming a parent while living with HIV. Olivia has co-presented workshops to diverse audiences at conferences throughout the US.
Who We Are

Positive Women's Network - United States of America (PWN-USA) is a national membership body of women living with HIV working to prepare and involve all women living with HIV, in all our diversity, including gender identity and sexual expression, in all levels of policy and decision-making to improve the quality of women’s lives.

PWN-USA applies a gender equity and human rights lens to the HIV epidemic to achieve federal policies grounded in the reality of women’s lived experiences.
Eliminate Stigma:
PWN-USA Strategic Plan

- Change Policy
  - Research & Policy Analysis
  - Advocacy
  - Coalition work

- Eliminate Stigma
  - Strategic communications
  - Media accountability

- Mobilize Advocates
  - Tools and resources
  - Peer-to-peer advocacy support
  - Regional Organizing

- Build Leadership
  - Train, support & nurture leaders
  - Technical assistance
  - Place WLHIV in decisionmaking
Intersectionality, HIV Justice, and the Future of Our Movement
Part 1: An Introduction to Intersectionality

“If we aren’t intersectional, some of us, the most vulnerable, are going to fall through the cracks.” - Kimberlé Williams Crenshaw

HIV thrives in conditions of structural inequity - where the workings of poverty, patriarchy, and other overlapping systems of injustice render community members vulnerable to acquiring HIV. Who is “most vulnerable” and who “falls through the cracks” is not static. We do not all experience these vulnerabilities in exactly the same way. However, the differences in our experiences - the learning edges of power and oppression, privilege and vulnerability - can, for our extraordinarily diverse HIV community, be sources of strength themselves.

Who We Are

We stand together as a group of HIV activists of color. We are Black lesbians. We are Black gay men. We are heterosexual. We are immigrants and descendants of immigrants. We are people living with HIV and people
Responding to Stigma

What’s HIV Got to Do With It? New York Post Violates Alleged Victim’s Rights in Strauss-Kahn Case

The Positive Women’s Network has

Tyler Perry's *Temptation* Sentences People With HIV to a Lifetime of Stigma and Isolation

From Positive Women's Network of the United States of America

April 16, 2013

"Tyler Perry's *Temptation* left me emotionally pained, angry and disappointed. Mr. Perry, a blockbuster maker, missed a genuine opportunity for honest and accurate community education around HIV. Instead, *Temptation* perpetuated HIV sensationalism and stigma. It demonized people living irresponsibly and portrayed women who acquire HIV as an undesirable, reclusive, sub-specialized group destined to live out their lives in suffering," commented Waheedah Shabazz-EI, a woman living with HIV.
#StandUptoStigma

- All of us – including those with the “power of the pen” – have a role to play in eliminating HIV stigma.
Presenter: Vickie Lynn, MSW, MPH

Vickie Lynn is a third-year doctoral student at the University of South Florida (USF), College of Public Health (COPH), Department of Community and Family Health (CFH), with a focus in Behavioral Health. Her research interests include examining behavioral health integration into primary care for people living with HIV, as well as other issues affecting access to care and treatment. A long-term survivor living with HIV since 1985, surviving an AIDS diagnosis, homelessness, and drug addiction, Vickie Lynn has spent the past few decades being an advocate for HIV issues.
Valerie Wojciechowicz has overcome many obstacles in her life, including addiction and obesity. These challenges and living with HIV (and its related stigmas) for 29 years have given her the determination to make a difference. Valerie uses her experiences to educate and empower others. In addition to providing services as an HIV testing counselor, Peer Navigator, Speaker, Trainer, and Fitness Professional, she has been instrumental in implementing Peer Programs in Florida. She works tirelessly to eliminate stigma and help improve the quality of life for others living with HIV and AIDS.
Eliminating Stigma from the Language of HIV Communications

Vickie Lynn, MSW, MPH
Valerie Wojciechowicz
Objectives

• Understand how language shapes our world
• Understand the history of language in relation to HIV.
• Explain the differences in stigmatizing and empowering language.
• Identify “people first language” and its importance.
• Explore the use of empowering language when talking or writing about self and others.
• Focusing on use of language may be the first place to start in order to address stigma, social exclusion, and discrimination against people living with HIV.

• Language
  – helps to shape our world
  – it describes and gives meaning to our lives
  – it persuades and changes minds
  – It can destroy or empower
Empowerment

Empowerment “is a multi-dimensional social process that helps people gain control over their own lives. It is a process that fosters power in people, in their lives, their communities, and in their society by acting on issues that they define as important” (Page & Czuba, 1999)
“Because reporting on HIV and AIDS ultimately deals with matters of life and death, and because many people will form their understanding of HIV and AIDS through the media, the story must be approached with clarity, precision, and sensitivity”

Kaiser Family Foundation. Reporting Manual on HIV/AIDS
HISTORY OF LANGUAGE USED IN THE HIV COMMUNITY
Terminology

- GRID (Gay Related Immune Deficiency)
- AIDS (Acquired Immunodeficiency Deficiency Syndrome)
- ARC (AIDS-Related Complex)
- Full-blown AIDS
- HIV - Human Immunodeficiency Virus
- Late stage HIV, end stage HIV, or Stage 3 (US) or Stage 4 (WHO)
Something is not correct on this magazine cover. What is it?
She has her father’s eyes and her mother’s AIDS.

Before you get pregnant, find out if you need to be tested.
AIDS causes blindness.

People with AIDS know there's a chance they'll lose their sight. But that's no reason for the people around them to lose sight of the fact that AIDS cannot be caught by touching someone. Or by putting AIDS out of work. Aids ACTION COMMITTEE

Keep AIDS out of the workplace. Which means the best way to fight AIDS is not with fear and anger, but with compassion and support.
"AIDS IS A WHITE MAN'S DISEASE."

FAMOUS LAST WORDS

People of color against AIDS, Information 206-1099
*Warning for next slide
Street slang

- Dirty
- The bug
- Bug catchers
- Monster
- Ninja
- The germ
- Diseased
- Are you *clean*?
"Language can neither be separated from our thoughts and feelings, nor from the social context in which it is used. Words and images create different conceptual realities of the phenomenon.” – Felicity Horne

Felicity Horne studies AIDS and language at the University of South Africa.
Slang in Africa

• Amesimamia Msumari | “Standing on a nail”; euphemism for being skinny ... referring to AIDS-related weight loss. (Tanzania, Kiswahili.)

• Departure Lounge | A person living with HVI is in the departure lounge awaiting death. (Zimbabwe.)

• F.T.T. | “Failure to thrive” (adapted from the medical phrase, now used to describe children living with HIV). (Zimbabwe.)

• Udlala Ilotto | “Playing the lotto” / ubambe ilotto – “won the lotto” (said of someone suspected of living with HIV; Lotto is the national lottery).

People First Language

• Rather than using 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.
Empowering Images
Using Language
<table>
<thead>
<tr>
<th>Stigmatizing</th>
<th>Preferred</th>
</tr>
</thead>
<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>Person living with HIV</td>
</tr>
<tr>
<td>AIDS or HIV carrier</td>
<td>Died of AIDS-related illness, AIDS-related complications or end stage HIV</td>
</tr>
<tr>
<td>Died of AIDS, to die of AIDS</td>
<td>Died of AIDS-related illness, AIDS-related complications or end stage HIV</td>
</tr>
</tbody>
</table>
## Language

<table>
<thead>
<tr>
<th>Incorrect</th>
<th>Preferred</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS virus</td>
<td>HIV</td>
</tr>
<tr>
<td>HIV virus</td>
<td>This is redundant use HIV</td>
</tr>
<tr>
<td>HIV or AIDS</td>
<td>HIV</td>
</tr>
<tr>
<td></td>
<td>AIDS (only when referring to AIDS)</td>
</tr>
<tr>
<td></td>
<td>HIV and AIDS</td>
</tr>
<tr>
<td>Risk group</td>
<td>Risk</td>
</tr>
<tr>
<td>Risky or unprotected sex</td>
<td>Be specific on what you are saying. Condomless sex, condomless sex with PrEP or without PrEP</td>
</tr>
<tr>
<td>Stigmatizing</td>
<td>Preferred</td>
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<tr>
<td>-----------------------</td>
<td>-----------------------------------------------------</td>
</tr>
<tr>
<td>Victim</td>
<td>Preferred</td>
</tr>
<tr>
<td>Sufferer</td>
<td>Do not use</td>
</tr>
<tr>
<td>Contaminated</td>
<td>Contaminated</td>
</tr>
<tr>
<td>Innocent (victim)</td>
<td>Children orphaned by loss of parents or guardians</td>
</tr>
<tr>
<td>AIDS orphans</td>
<td>who died of AIDS related complications</td>
</tr>
<tr>
<td>Stigmatizing</td>
<td>Preferred</td>
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<tr>
<td>--------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>HIV infected mother</td>
<td>Mother living with HIV</td>
</tr>
<tr>
<td>Mother to child transmission</td>
<td>Vertical transmission</td>
</tr>
<tr>
<td>AIDS Orphans</td>
<td>Children who lost both their parents</td>
</tr>
<tr>
<td>Bodily fluids</td>
<td>Be precise on which fluid you are referring to blood, semen, vaginal fluid or secretions, breast milk, amniotic fluid, pre-ejaculate</td>
</tr>
</tbody>
</table>
## Language

<table>
<thead>
<tr>
<th>Stigmatizing</th>
<th>Preferred</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intravenous drug users</td>
<td>Person who injects drugs or person who uses drugs</td>
</tr>
<tr>
<td>Sharing (needles, syringes)</td>
<td>Use of non-sterile injecting equipment</td>
</tr>
<tr>
<td>Prostitue or prostitution</td>
<td>Sex worker, sale of sexual services</td>
</tr>
<tr>
<td>Promiscuous</td>
<td>This is a value judgment and should be avoided.</td>
</tr>
<tr>
<td></td>
<td>Use - Having multiple partners</td>
</tr>
</tbody>
</table>
## Language

<table>
<thead>
<tr>
<th>Stigmatizing</th>
<th>Preferred</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fight against AIDS</td>
<td>Response to AIDS or AIDS response</td>
</tr>
<tr>
<td>HIV/AIDS (HIV slash AIDS)</td>
<td>Use HIV when appropriate and use AIDS when appropriate.</td>
</tr>
<tr>
<td>AIDS test</td>
<td>HIV test</td>
</tr>
<tr>
<td>To catch AIDS</td>
<td>An AIDS diagnosis, developed AIDS</td>
</tr>
<tr>
<td>To contract AIDS</td>
<td>To contract HIV</td>
</tr>
<tr>
<td>To catch HIV</td>
<td></td>
</tr>
<tr>
<td>Compliant</td>
<td>Adherent</td>
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Self Talk

Infected
Self Talk

Positive
Intro to Activity
Example

• I was **infected with HIV** when I was a teenager.

• I **contracted HIV** when I was a teenager.
Example

- Women are most likely to be infected with HIV through heterosexual contact.
- Women are most likely to contract HIV through heterosexual contact.
• Cardiovascular disease has become a major concern among **HIV-infected individuals**.

• Cardiovascular disease has become major concern among **people living with HIV**
Activity

Your responses . . .
What can we as advocates, activists, and other professionals do to help reduce the stigmatizing language?

• Use appropriate terminology
• Use empowering terminology
• Use non-stigmatizing language and images
• Portray people with HIV living positively, not depressed or ostracized
• Empower yourself and others
I AM NOT

"DYING HELPLESS
SICK BEING PUNISHED
GUILTY OR DIRTY"

I AM HIV
POSITIVE

UPDATE YOUR THINKING.
END THE STIGMA.

LIVE HIV NEUTRAL

THE STIGMA
PROJECT
References


Thank You

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