Why Language Matters:

Facing HIV Stigma in Our Own Words

Thursday, November 2, 2017

Together, we can change the course of the HIV epidemic...one woman at a time.

#onewomanatatime                                                            #thewellproject
Speakers and Panelists


**Olivia Ford**, consulting editor, The Well Project

**Krista Martel**, executive director, The Well Project (*moderator*)

**Tiommi Jenae Luckett**, The Well Project, PWN-USA, US PLHIV Caucus

**Venita Ray**
Legacy Community Health

**Yamini Oseguera-Bhatnagar**, HIVE, PleasePrEPme.org

**Caroline Watson**, HIVE
About The Well Project

• Non-profit organization with a mission to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls
• Leverages technology to improve health outcomes and increase quality of life for women and girls living with HIV
• Provides accessible and comprehensive #information, #community support, and #advocacy building
• Access our resources and join our community at www.thewellproject.org
HIVE: a hub of positive reproductive & sexual health

Founded in 1989 at San Francisco General Hospital

Our Mission
Advancing reproductive and sexual wellness for individuals, families and communities affected by HIV in San Francisco and beyond.

Our Vision
A world where people affected by HIV have safe pregnancies, reproductive autonomy, access to state-of-the-art health care, and enjoyable sex lives.
Search for PrEP providers in your area. In collaboration with PrEPLocator.org.

Local HIV-prevention resources in English and Spanish for patients and providers in all 50 states.

Helping Californians find PrEP/PEP services in their area through chat, text and telephone, in English and Spanish.


In collaboration with Project Inform and the Office of AIDS, California Department of Public Health.
About Positive Women’s Network-USA

• Founded in 2008 by 28 diverse women living with HIV
• Today: 3,000 members nationwide, 7 formally affiliated regional chapters

Positive Women’s Network-USA is the only national organization in the U.S. led by and for women living with HIV

Our mission: To prepare and involve women living with HIV, in all our diversity, including gender identity and sexual expression, in all levels of policy and decision-making.
About WATCH!

- **WATCH!** (Women’s Advocacy and Treatment Coalition on HIV) is an ongoing HIV treatment advocacy and capacity-building webinar series.
- The **WATCH!** 2017 series will take place throughout the year and will include 3-4 webinars.
- Certificates will be issued for **each** webinar for those who either attend the live webinar or view the recording and take webinar pre- and post-test.
  - Webinars will be recorded and can be accessed up to one month after they take place on our website.
Webinar Details

- Webinar will last approximately 90 minutes with Q&A.
- Use live chat box on left side to enter questions while presenters talk; questions will be put in queue.
- If you are listening to webinar via your phone, please enter second audio pin to connect your phone to computer * (3-digit number)#.
- Participants’ lines will be muted (can unmute during Q&A if requested).
  - To unmute your phone, press *6 or click on microphone icon at the top of your screen (if using computer microphone).
Agenda

• Introductions
• Facing HIV stigma in our own words
  – An introduction to why language matters
  – HIV stigma communication and preferred language
  – Empowering women through language
  – Language and advocacy
• Panel discussion
• Q&A
Why Language Matters

Vickie Lynn, The Well Project

Together, we can change the course of the HIV epidemic...one woman at a time.

#onewomanatatime  #thewellproject

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Poll Question:
Have you ever encountered words that hurt (also known as stigmatizing language) about HIV from family members, friends, or colleagues?

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Why Language Matters

- Have you ever heard a person living with HIV describe themselves as “I am HIV”?
- Do the words “infection” or “infected” feel negative to you?
- Are you offended when you are referred to by your health condition first, instead of as a person first?

The words people use to talk about HIV affect the way people living with HIV feel about themselves. These words also have an impact on how others perceive people living with HIV.

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Why Language Matters

• Helps shape understanding of the world we live in
• Is the foundation of our stories
• Describes who we are and how we connect with others, with ourselves

Words can inspire, **empower**, bring us hope ...

They can also bully, scare, destroy our sense of self

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Why Language Matters

Women may experience multiple forms of oppression, discrimination

- Based on gender, race, sexual identity, socioeconomic status, or other factors
- This oppression is often reinforced through language
  - An aggressive, powerful woman: “bitch”
  - A man with same qualities: “ambitious,” viewed with respect
- Adding an HIV diagnosis can magnify this oppression
  - Affects self-worth, confidence, self-identity

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Why Language Matters

• Language that reinforces stigma and discrimination, repeated over years, affects health and well-being of women living with HIV (WLHIV)
  – Stigma and stress have negative effect on women’s quality of life
  – Can affect her family, children, job, pregnancies
  – Stress of stigma can affect immune system

• HIV-related stigma affects prevention, deters people from being tested for HIV, makes disclosure harder

• Rare to find a woman living with HIV who has not felt stigmatized in some way

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Poll Question:
Have you ever encountered words that hurt (also known as stigmatizing language) about HIV in a healthcare setting?
What Is HIV Stigma Communication?

• Can exist in language, labels, messages used to educate or talk about a health condition/group of people

• Some conditions stigmatized more than others; seen as moral issue/character flaw, instead of biological disease
  – Leprosy (“lepers”), mental health (“the mentally ill”), substance use (“addicts,” “junkies”), HIV (“infected”)

• Reducing people to a label dismisses their humanity, sets them apart from others
What Is HIV Stigma Communication?

• The narrative about HIV includes myths and false stereotypes that:
  – Stigmatize HIV
  – Isolate people living with HIV

• Stigmatizing stereotypes make for good rumors, gossip
  – News media often uses them to get attention
  – Emotions most often shared in rumors are fear, anger, disgust

• Rumors become part of our social environment, regardless of whether they are true
Homos prone to rare cancer

DOCTORS in New York and California have diagnosed a rare form of cancer in people of whom were previously healthy. It is primary known to affect homosexual men, and doctors warn that it is highly contagious.

AIDS fear: dentist ban on gays

SOME DENTISTS in Australia have refused to treat homosexual patients because they fear catching AIDS, according to Melbourne's gay community.

Mr Adam Carr, a spokesman for the new Victorian AIDS action committee, said there had also been cases of homosexual patients being put into hospital isolation wards even though they showed no symptoms of AIDS.

Mr Carr said the aim of the action was to stop the medical profession scapegoating the issue in a way that was not needed.

AIDS VIRUS KILLS MAN IN BRITAIN

Call for homosexual to spot gay clients

Crucial discovery on HIV

SA researchers celebrate breakthrough study

AIDS IS THE WRATH OF GOD, SAYS VICAR

Ex-ballet boss is victim 53
Georgia lawmaker: Can people with HIV be 'legally' quarantined?

By Ben Tinker, CNN

Updated 12:17 PM ET, Sun October 22, 2017
What Is HIV Stigma Communication?

HIV stigma communication is found in:

• History of the HIV epidemic
• Media
• Social marketing prevention campaigns
• Policies
• Research literature
• Movies
• *Our own heads*

*Language we hear (from family, friends, news headlines, research articles, etc.) becomes language we use to describe ourselves and others*
Two Kinds of Stigma

**External stigma** comes from what we:
- Hear from family, friends, healthcare providers, etc.
- Read or hear in the media

**Internal stigma**:
- Comes from self-judgment and **negative self-talk** we hear in our heads
- Is developed by our life experiences -- with stigma, discrimination, shame, guilt

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Poll Question:
Do you feel like words that hurt (or stigmatizing words) have affected how you think about yourself and about living with HIV?
Negative Self-Talk

• Things we tell ourselves that define who we are

• Stories we tell ourselves may include:
  – We are not good enough, strong enough, smart enough, beautiful enough
  – We deserve everything challenging that has happened to us
  – We are damaged goods

• One of the first places to start to make change is in the language we hear in our own heads

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What Is People-First Language?

• Puts person before illness or label
• Describes and respects who they are, not what they have been diagnosed with
• Helps eliminate prejudice; removes value judgments
• Describing people by labels or medical diagnoses devalues and disrespects them as individuals
  – You never hear “cancerous people” or “I am cancer positive”
  – But you often hear “HIV-infected woman”
  – Preferred phrase is “woman living with HIV;” refers to person first, before mentioning their health condition

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The Denver Principles

• Written by HIV advocates in 1983
• Called for use of person-first language:

“We condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others.

We are 'People With AIDS.'"

• Describes people living with HIV as human, valuable; shows respect, compassion
### Preferred Language About HIV

<table>
<thead>
<tr>
<th>Stigmatizing Language (&quot;Try not to use&quot;)</th>
<th>Preferred Language (&quot;Use this instead&quot;)</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV-infected person</td>
<td>Person living with HIV; PLHIV</td>
</tr>
<tr>
<td>HIV or AIDS patient, AIDS or HIV carrier</td>
<td>Never use “infected” when referring to a person</td>
</tr>
<tr>
<td>Positives or HIVers</td>
<td>Died of AIDS-related illness, AIDS-related complications, end-stage HIV</td>
</tr>
<tr>
<td>Died of AIDS, to die of AIDS</td>
<td>Died of AIDS-related illness, AIDS-related complications, end-stage HIV</td>
</tr>
<tr>
<td>AIDS virus</td>
<td>HIV (AIDS is a diagnosis, not a virus; it cannot be transmitted)</td>
</tr>
<tr>
<td>Full-blown AIDS</td>
<td>There is no medical definition for this phrase; simply use “AIDS,” or “Stage 3 HIV”</td>
</tr>
<tr>
<td>HIV virus</td>
<td>This is redundant; simply use “HIV”</td>
</tr>
<tr>
<td>Zero new infections</td>
<td>Zero new HIV transmissions</td>
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[www.thewellproject.org](http://www.thewellproject.org)
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<td>HIV infections</td>
<td>HIV transmissions; diagnosed with HIV</td>
</tr>
<tr>
<td>HIV infected</td>
<td>Living with HIV; diagnosed with HIV</td>
</tr>
<tr>
<td>Became infected</td>
<td>Contracted or acquired; diagnosed with</td>
</tr>
<tr>
<td>Serodiscordant couple</td>
<td>Serodifferent, magnetic, mixed-status</td>
</tr>
<tr>
<td></td>
<td>couple</td>
</tr>
<tr>
<td>Mother-to-child transmission</td>
<td>Vertical transmission or perinatal</td>
</tr>
<tr>
<td></td>
<td>transmission</td>
</tr>
<tr>
<td>Victim, innocent victim, sufferer,</td>
<td>Person living with HIV; survivor; warrior</td>
</tr>
<tr>
<td>contaminated, infected</td>
<td>Again, never use the term “infected” when</td>
</tr>
<tr>
<td></td>
<td>referring to a person</td>
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<td>To catch AIDS, to contract AIDS, transmit AIDS, to catch HIV</td>
<td>An AIDS diagnosis; developed AIDS; to contract HIV (AIDS is a diagnosis; cannot be passed from one person to the next)</td>
</tr>
<tr>
<td>Compliant</td>
<td>Adherent</td>
</tr>
<tr>
<td>Prostitute or prostitution</td>
<td>Sex worker; sale of sexual services; transactional sex</td>
</tr>
<tr>
<td>Promiscuous</td>
<td>This is a value judgment and should be avoided. Use &quot;multiple partners&quot;</td>
</tr>
<tr>
<td>Unprotected sex</td>
<td>Sex without barriers or treatment-as-prevention methods, condomless sex, condomless sex with (or without) PrEP</td>
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<td>Death sentence, fatal condition, life-threatening condition</td>
<td>HIV is a chronic and manageable condition when people are in care and treatment</td>
</tr>
<tr>
<td>“Tainted” blood, “dirty” needles</td>
<td>Blood containing HIV; shared needles</td>
</tr>
<tr>
<td>Clean, as in “I am clean, are you”</td>
<td>Avoid this term. Referring to being “clean” suggests that those living with HIV are dirty</td>
</tr>
<tr>
<td>End HIV, End AIDS</td>
<td>End HIV transmission, end HIV-related deaths Be specific: are we ending AIDS diagnoses or are we ending the transmission of HIV?</td>
</tr>
</tbody>
</table>
**Empowering Women Through Language**

- To address *internalized stigma*, we can change messages we say to ourselves
  - Helps to change self-image
  - We begin to treat ourselves with more compassion

- Things you can do to make these changes:
  - Mirror work and self-affirmations
    - Involves looking in the mirror, saying positive affirmations (messages we tell ourselves)
  - Examining and changing our self-talk

- Research shows this helps women improve their self-image, confidence, outlook, health, well-being

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Examining and Changing Our Self-Talk

• Write down thoughts, messages you tell yourself (negative self-talk)
  – E.g., “I am infected with a horrible disease; no one will love me”

• Review messages by yourself or with friends

• Examine specific language you choose to describe yourself and current situation; ask yourself:
  – Are these thoughts true?
  – Are these thoughts helpful?
  – Do they tear me down or empower and lift me up?

• Try replacing old image with a new, more accurate image of yourself (positive self-talk)
  – E.g., “I am living with HIV and I am lovable”

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Important to note:

• Terms and phrases like "living with AIDS" and “I am HIV-positive” have been empowering to many people living with HIV

• For others, these terms may not describe their experience; may feel stigmatizing

• Words and language mean different things to different people, at different times in their lives

Allow others to define themselves as they wish; always start from a place of respect

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Poll Question:
Have you ever corrected someone’s use of words that hurt (also known as stigmatizing language) about HIV?
Language and Advocacy

Olivia Ford, The Well Project

Together, we can change the course of the HIV epidemic...one woman at a time.

#onewomanatatime #thewellproject

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Different Kinds of Advocacy

- **Self-Advocacy**: speaking up for yourself
- **Individual Advocacy for Others**, including **Peer Advocacy**: speaking up on behalf of someone else, and/or supporting others to speak up for themselves
- **Community Advocacy**: getting together with others to speak up about changes that need to be made on a larger scale
- **Political/Public Advocacy**: speaking up to those in power on a national or international level

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Every time you speak up for yourself or others, you are an advocate

• It may be as simple as:
  – Letting the cashier at the grocery store know that she overcharged you for an item
  – Telling a friend why a term they use to describe people with HIV is offensive to you

• It can also be more difficult, like:
  – Filing a complaint with HR for discrimination at your job
  – Asking your healthcare provider not to use the term “HIV infected” when they talk about your care
Individual Advocacy for Others and Peer Advocacy

• Supporting someone when they need help, or trying to find a solution when someone has a problem
• Involves supporting another person living with HIV around an HIV-related issue
  – Based on your shared experience with HIV

**Individual advocate for others:**
• Contacting school officials after learning a child was bullied
• Writing a letter to a news outlet to oppose the way a person living with HIV was talked about in their coverage

**Peer Advocate**
• Helping someone in your support group who’s having trouble understanding treatment materials
• Helping a friend think through what she wants to say to her provider about a stigmatizing term they use
Community Advocacy

- A larger version of the individual advocacy that you may already practice in your daily life
- Involves groups of people acting to affect positive change
- Before getting involved, decide how comfortable you are about disclosing your HIV status
  - This personal decision requires careful thought and discussion
- Whether you decide to be public or private with your status, you can still be a community advocate:
  - Local HIV awareness and fundraising events, such as an AIDS walk
  - Joining a patient advisory group at an HIV research site, an ASO, or an HIV planning council
  - #LanguageMatters, #NotYourInfection, #WeAreALLClean

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Campaigns around language have reached the ears of federal officials – and changed agencies’ actions

- U Equals U
- CDC language changes – “sex without condoms,” language around serodifferent couples and conception
- AIDS.gov → HIV.gov
Changing Language, Making Change

- For many WLHIV, thinking about and making changes to their HIV language has been an empowering experience.
- For some, it has led to pointing out stigmatizing *language used by others*: family, friends, providers.
- Others may begin *reaching out to media* when outlets use inappropriate language:
  - Letters to the editor, social media.
- Some people join campaigns working on language issues:
  - HIV advocates have won changes to stigmatizing language used by *large institutions*.

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These are powerful ways to be an advocate; they don't all involve being a loud voice in a big crowd

• Each time someone questions (even to themselves) a phrase that fuels stigma/ignorance, they contribute to building hope

• This is part of changing our culture from one that disrespects WLHIV to one that uses language to support the **power and dignity of all women**
Panel Discussion

with Tiommi Jenae Luckett, Venita Ray, Yamini Oseguera-Bhatnagar and Caroline Watson

Led by Vickie Lynn and Krista Martel
To learn more:

- [Why Language Matters: Facing HIV Stigma in Our Own Words](#)

For more fact sheets and to connect to our community of women living with HIV, visit:

- [www.thewellproject.org](http://www.thewellproject.org)
- [www.facebook.com/thewellproject](http://www.facebook.com/thewellproject)
- [www.twitter.com/thewellproject](http://www.twitter.com/thewellproject)
Additional Resources

- HIVE: [www.HIVEonline.org](http://www.HIVEonline.org)
- Please PrEP Me: [www.pleaseprepme.org/women](http://www.pleaseprepme.org/women)
- PWN-USA: [www.pwn-usa.org](http://www.pwn-usa.org)
- #LanguageMatters: [https://www.hiveonline.org/language-matters/](https://www.hiveonline.org/language-matters/)
- #NotYourInfection: [https://www.facebook.com/NotYourHIVInfection/](https://www.facebook.com/NotYourHIVInfection/)
- Language, Identity and HIV (Journal of the International AIDS Society)
- Five Things Media Makers Can Do NOW to Stand Up to HIV Stigma (PWN-USA)
- HIV and AIDS: Language and the Blame Game (Open Democracy)
- How the Denver Principles Changed AIDS (and Health Care) Forever (My Fabulous Disease)
- What Is Mirror Work? (LouiseHay.com)
- Microaggression and Bias in the HIV Community -- and What We Can Do About It (TheBody.com)
Post-Assessment Test

Please go to
https://www.surveymonkey.com/r/WATCH2017_Posttest3

to take today’s webinar Post-Assessment Test

An email message will be sent out on in the coming days, with
the link to the webpage for today’s webinar that has links to
pre- and post-assessment tests, the webinar recording, and
additional resources on this topic.

Thank you for your participation!
Thank You!

Questions & Answers

The Q & A will come from the questions submitted to the presenters through the chat box during the webinar session.