



Women's Advocacy and
Treatment Coalition on HIV

A program of The Well Project



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

www.thewellproject.org

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Speakers and Panelists



Vickie Lynn, community advisory board, *A Girl Like Me*, The Well Project; USF doctoral candidate



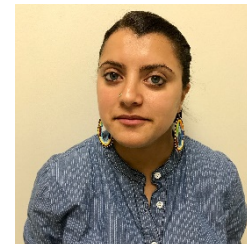
Tiommi Jenae Luckett, The Well Project, PWN-USA, US PLHIV Caucus



Olivia Ford, consulting editor, The Well Project



Venita Ray
Legacy Community Health



Yamini Oseguera-Bhatnagar, HIVE, PleasePrEPme.org



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



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.

HIVEonline.org

hive 
POWERhealth

hive  clinic
Bay Area Perinatal AIDS Center

::Hangouts with HIVE::

Webinars on a variety of topics, presented via Google Hangouts on Air

HIVE Blog

Blogs written by patients, consumers, and providers

hive  tools

hive
weareallwomen

hive
PROMEN
please
PrEP
me
.org





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.

A worldwide directory of PrEP providers. Country specific resource pages in development.

In collaboration with Project Inform and the Office of AIDS, California Department of Public Health.



Your Home For PrEP Access

Palm Cards & Digital Assets

La PrEP es

- Una abreviación de profilaxis "pre-exposición" o anterior a la exposición
- Una pastilla que se toma todos los días para prevenir el VIH
- Segura
- Eficaz en más de un 90% si se toma diariamente

ENTÉRATE MEJOR EN  **WOMEN**

PARA ASISTENCIA SOBRE CÓMO OBTENER LA PREP EN SF LLAMA O ENVÍA UN MENSAJE DE TEXTO AL 415.985.PREP (7737). O TAMBIÉN, PUEDES VISITAR PLEASEPREPME.ORG O LLAMAR AL 415.476.3443.

AS WOMEN, IT IS IMPORTANT TO HAVE AN HIV PREVENTION METHOD THAT IS IN OUR HANDS.

Consider PrEP if you are a woman who:

- Worries about her HIV risk
- Has condomless sex with partners of unknown HIV status
- Recently had gonorrhea or syphilis
- Wants to have a baby with a man living with HIV
- Injects drugs
- Exchanges sex for \$/food/housing/drugs

has a male sex partner who:

- Has condomless sex with others
- Has sex with men
- Injects drugs
- Has HIV or sexually transmitted infections

contact@pleaseprepme.org

 **WOMEN**

CHAT WITH US.

 **CONNECT**
Chat with us about PrEP/PEP.

 **DIRECTORY**
Search for providers in your area.

 **RESOURCES**
Local HIV-prevention resources.

Daily PrEP Protects Against HIV.
All Genders. All Sexes.

 **CONNECT**

¡CHATEA CON NOSOTROS!

 **CONNECT**
Chatea con nosotros sobre la PrEP/PEP.

 **DIRECTORY**
Busca proveedores en tu área.

 **RESOURCES**
Servicios locales de prevención del VIH.

PrEP, una pastilla diaria para prevenir el VIH. Para todos los géneros y sexos.

 **CONNECT**

CONSIDERING PrEP?

A daily pill that can help you stay HIV-negative.
It might be right for you.

FIND A PROVIDER: pleaseprepme.org
RESOURCES: pleaseprepme.org/resources

FOR ALL GENDERS.



¿ESTÁS CONSIDERANDO TOMAR PrEP?

Es una pastilla que puede ayudarte a mantenerte VIH negativo/a.
¡Ésta puede ser la opción para ti!

BUSCA UN PROVEEDOR: pleaseprepme.org
RECURSOS: pleaseprepme.org/resources

PARA TODOS LOS GÉNEROS.





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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

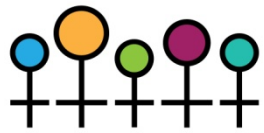
Our mission: To *prepare and involve* women living with HIV, in all our diversity, including gender identity and sexual expression, in all levels of policy and decision-making.



POSITIVE WOMEN'S NETWORK USA

Sisterhood · Solidarity · Action

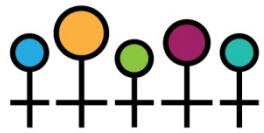
www.pwn-usa.org



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About *WATCH!*

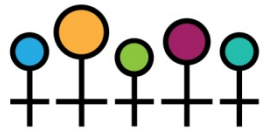
- *WATCH!* (Women's Advocacy and Treatment Coalition on HIV) is an ongoing HIV treatment advocacy and capacity-building webinar series
- The *WATCH!* 2017 series will take place throughout the year and will include 3-4 webinars
- Certificates will be issued for each webinar for those who either attend 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



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Webinar Details

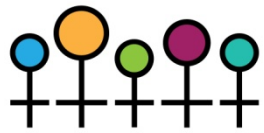
- Webinar will last approximately 90 minutes with Q&A
- Use live chat box on left side to enter questions while presenters talk; questions will be put in queue
- If you are listening to webinar via your phone, please enter second audio pin to connect your phone to computer * (3-digit number)#
- Participants' 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)



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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



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Why Language Matters

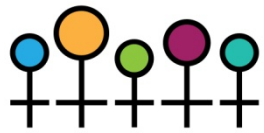
Vickie Lynn, The Well Project

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

#onewomanatatime

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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?

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***

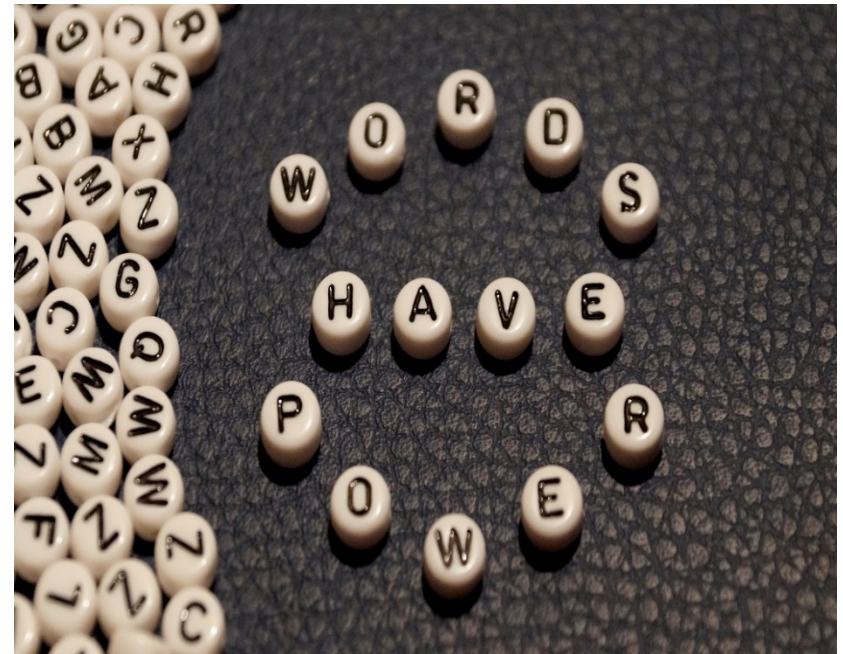
These words also have an impact on how others ***perceive*** people living with HIV

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



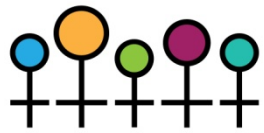
Why Language Matters

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

Why Language Matters

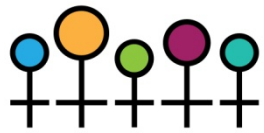
- Language that reinforces stigma and discrimination, repeated over years, affects health and well-being of women living with HIV (WLHIV)
 - Stigma and stress have negative effect on women's quality of life
 - Can affect her family, children, job, pregnancies
 - Stress of stigma can affect immune system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

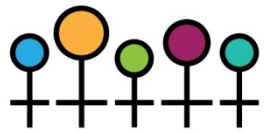
Have you ever encountered words that hurt (also known as stigmatizing language) about HIV in a healthcare setting?



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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



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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

THEN

Homos prone to rare cancer

DOCTORS in New York and California have diagnosed among homosexual men 41 cases of a rare and often rapidly fatal form of cancer.

Doctors who found 20 cases of Kaposi's sarcoma in New York and six cases in California are alerting other physicians of homosexual men to shorten the delay in offering chemotherapy.

Eight of the victims died less than two years after the diagnosis was made.

There is no national registry of victims in the United States. The nationwide incidence of Kaposi's sarcoma in the past year was estimated by the Centers for Disease Control at about two cases per 100,000 people.

Gays indignant over 'hysteria' on AIDS

SYDNEY. — Voyeurism and ignorance within the medical profession and labelling of AIDS as the "gay cancer," according to Sydney gay activist Lex Watson.

Gays were not the highest risk group on a percentage basis, he told a seminar on AIDS and hepatitis in Sydney yesterday.

The number of cases of acquired immune deficiency syndrome among drug abusers, and haemophiliacs was proportionally much higher than among the 12 million US gay men, he said.

The seminar was organised by Merck, Sharp and Dohme, manufacturers of the hepatitis B vaccine, to reassure the public that although blood donors for the vaccine's production included gay men, it did not carry a risk of transmitting AIDS.

Mr Watson said: "The political and social power of medicine was clearly illustrated in the initial labelling of deficiency syndrome — before any reliable statistics were available."

Only pressure from US gays forced the change to AIDS, he said, but the extent of the damage already done to the gay community.

Merck, Sharp and Dohme, manufacturers of the hepatitis B vaccine, to reassure the public that although blood donors for the vaccine's production included gay men, it did not carry a risk of transmitting AIDS.

Mr Watson said: "The political and social power of medicine was clearly illustrated in the initial labelling of deficiency syndrome — before any reliable statistics were available."

Only pressure from US gays forced the change to AIDS, he said, but the extent of the damage already done to the gay community.

"There are thousands of documented cases, both here and in the United States of discrimination against gays within the health profession, the workplace, and even among delivery firms based on the fear of AIDS," he said.

The director of the Australian Hepatitis Reference Centre, Dr Ian Gust, released figures showing cases of AIDS among people vaccinated for hepatitis B to be no higher than similar risk non-vaccinated groups.

Dr Gust said that because hepatitis B was a virus which could not be grown in a laboratory, the vaccine could be produced only by using antibodies from the blood plasma of people who had had the disease.

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 committee was to stop "scapegoating" the gay community.

RARE CANCER SEEN IN 41 HOMOSEXUALS

Break Occurs Among Men in New York and California — 8 Died Inside 2 Years

By LAWRENCE K. ALTMAN.
Doctors in New York and California have diagnosed among homosexual men 41 cases of a rare and often rapidly fatal form of cancer. Eight of the victims died inside 24 months after the diagnosis was made.

The cause of the outbreak is unclear and there is as yet no evidence of transmission. But the doctors who have made

Daily Mail

20p
MONDAY, NOVEMBER 16, 1981
Patient catches disease after blood transfusion

AIDS VIRUS KILLS MAN IN BRITAIN

SA researchers celebrate breakthrough on HIV

Infected people give clues to making a vaccine

SA researchers celebrating a breakthrough on HIV (human immunodeficiency virus) which causes AIDS (acquired immunodeficiency syndrome).

The researchers, led by Dr. Robert Gallo, of the National Institutes of Health, announced that they had isolated the virus from a patient who had died of AIDS.

The researchers said that the virus was found in the blood of the patient, and that it was the same virus that had been found in other patients with AIDS.

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A cautious world of AID and gays...

From Page 1
"The disease just happened to crop up in the gay community," he said.

Until the syndrome was understood more fully, he said, homosexuals and heterosexuals alike needed to think carefully about casual sexual encounters.

Mr Glynn said he had been living with a man for three years and they had shared each other's life, but now they had agreed to restrict those encounters.

Mr Watson said Government health authorities should counter

AIDS IS THE WRATH OF GOD, SAYS VICAR

By HUGH WHITELOW
A VICAR yesterday branded the gay plague AIDS as the wrath of God.

The Rev. Owen Leighton-Williams claimed homosexuals attracted the Lord's

Ex-ballet boss is victim 53

NOW



Health » Georgia lawmaker: Can people with HIV be 'legally' quarantined?

Live TV

U.S. Edition +



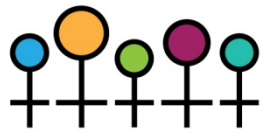
Georgia lawmaker: Can people with HIV be 'legally' quarantined?



By **Ben Tinker**, CNN

⌚ Updated 12:17 PM ET, Sun October 22, 2017





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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***

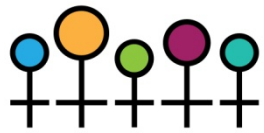
Two Kinds of Stigma

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



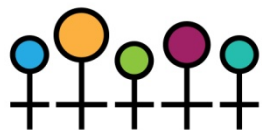
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Poll Question:

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***



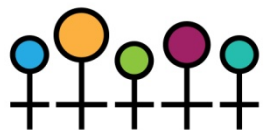
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What Is People-First Language?

- 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

The Denver Principles

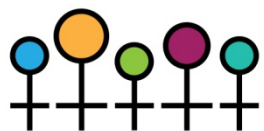
- Written by HIV advocates in 1983
- Called for use of person-first language:
"We condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others.
We are 'People With AIDS.'"
- Describes people living with HIV as human, valuable; shows respect, compassion



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Preferred Language About HIV

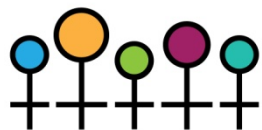
Stigmatizing Language ("Try not to use")	Preferred Language ("Use this instead")
HIV-infected person	Person living with HIV; PLHIV
HIV or AIDS patient, AIDS or HIV carrier Positives or HIVers	Never use "infected" when referring to a person
Died of AIDS, to die of AIDS	Died of AIDS-related illness, AIDS-related complications, 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 "AIDS," or "Stage 3 HIV"
HIV virus	This is redundant; simply use "HIV"
Zero new infections	Zero new HIV transmissions



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Preferred Language About HIV

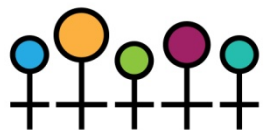
Stigmatizing Language ("Try not to use")	Preferred Language ("Use this instead")
HIV infections	HIV transmissions; diagnosed with HIV
HIV infected	Living with HIV; diagnosed with HIV
Became infected	Contracted or acquired; diagnosed with
Serodiscordant couple	Serodifferent, magnetic, mixed-status couple
Mother-to-child transmission	Vertical transmission or perinatal transmission
Victim, innocent victim, sufferer, contaminated, infected	Person living with HIV; survivor; warrior Again, never use the term "infected" when referring to a person



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Preferred Language About HIV

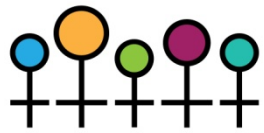
Stigmatizing Language ("Try not to use")	Preferred Language ("Use this instead")
To catch AIDS, to contract AIDS, transmit AIDS, to catch HIV	An AIDS diagnosis; developed AIDS; to contract HIV (AIDS is a diagnosis; cannot be passed from one person to the next)
Compliant	Adherent
Prostitute or prostitution	Sex worker; sale of sexual services; transactional sex
Promiscuous	This is a value judgment and should be avoided. Use "multiple partners"
Unprotected sex	Sex without barriers or treatment-as-prevention methods, condomless sex, condomless sex with (or without) PrEP



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Preferred Language About HIV

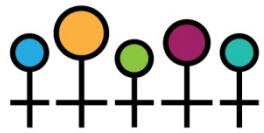
Stigmatizing Language ("Try not to use")	Preferred Language ("Use this instead")
Death sentence, fatal condition, life-threatening condition	HIV is a chronic and manageable condition when people are in care and treatment
"Tainted" blood, "dirty" needles	Blood containing HIV; shared needles
Clean, as in "I am clean, are you"	Avoid this term. Referring to being "clean" suggests that those living with HIV are dirty
End HIV, End AIDS	End HIV transmission, end HIV-related deaths Be specific: are we ending AIDS diagnoses or are we ending the transmission of HIV?



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Empowering Women Through Language

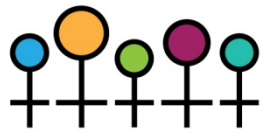
- To address ***internalized stigma***, we can change messages we say to ourselves
 - Helps to change self-image
 - We begin to treat ourselves with more compassion
- Things you can do to make these changes:
 - Mirror work and self-affirmations
 - Involves looking in the mirror, saying positive affirmations (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”



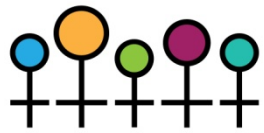
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Language and Empowerment

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

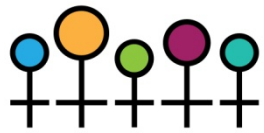
Allow others to define themselves as they wish; always
start from a place of respect



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Poll Question:

Have you ever corrected someone's use of words that hurt (also known as stigmatizing language) about HIV?



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Language and Advocacy

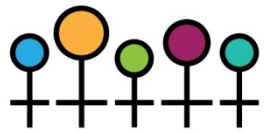
Olivia Ford, The Well Project

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

#onewomanatatime

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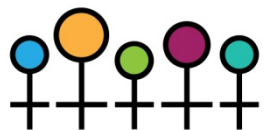
Different Kinds of Advocacy

- **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

Self-Advocacy

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



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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

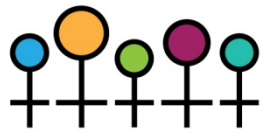
- Helping someone in your support group who's having trouble understanding treatment materials
- Helping a friend think through what she wants to say to her provider about a stigmatizing term they use

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

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

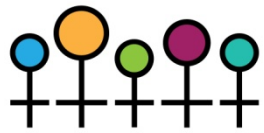
- U Equals U
- CDC language changes – “sex without condoms,” language around serodifferent couples and conception
- AIDS.gov → HIV.gov



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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***

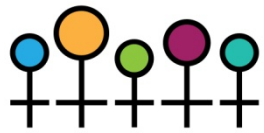


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Changing Language, Making Change

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***

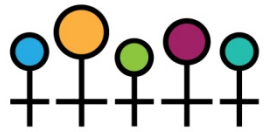


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Panel Discussion

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

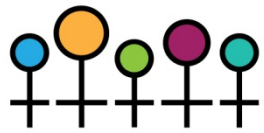
Led by Vickie Lynn and Krista Martel



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Learn More!

- 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
 - www.facebook.com/thewellproject
 - www.twitter.com/thewellproject



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Additional Resources

- HIVE: www.HIVEonline.org
- Please PrEP Me: www.pleaseprepme.org/women
- PWN-USA: www.pwn-usa.org
- #LanguageMatters: <https://www.hiveonline.org/language-matters/>
- #NotYourInfection: <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

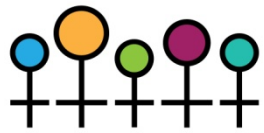
Please go to

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!



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Thank You!



Questions & Answers

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