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Why Language Matters: *Facing HIV Stigma in Our Own Words*

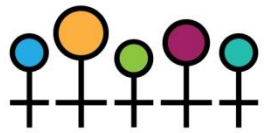
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Together, we can change the course of the HIV epidemic...one woman at a time.

#onewomanatatime

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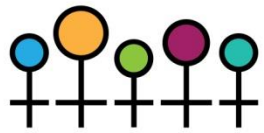
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Why Language Matters

- *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



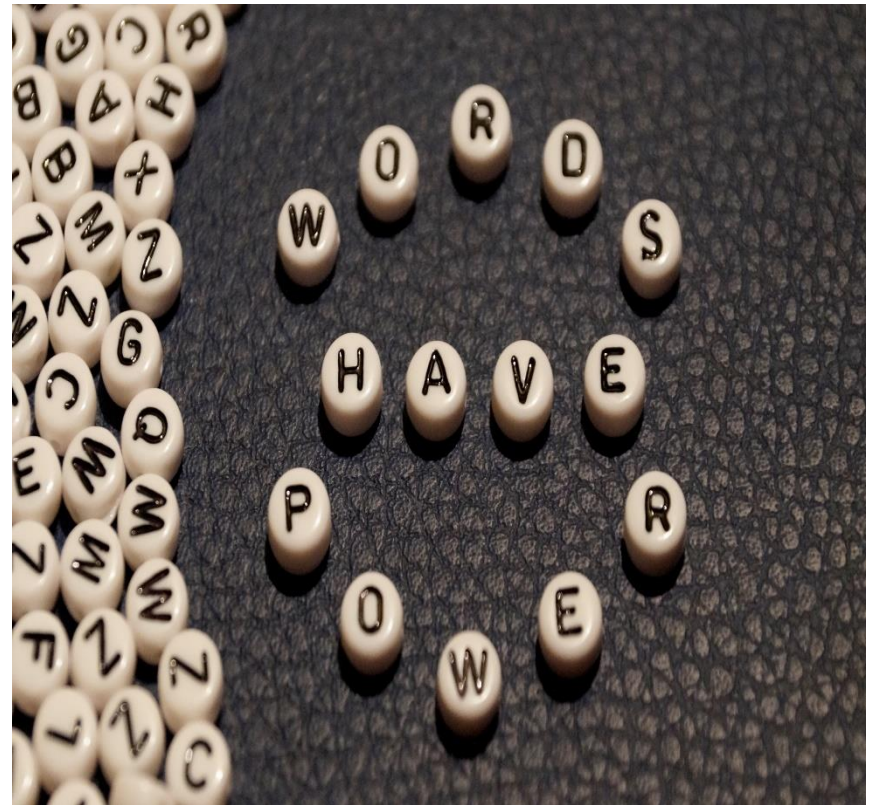
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Why Language Matters

- Helps shape understanding of the world we live in
- Is the foundation of our stories
- Describes who we are, 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
- Often reinforced through language
 - An aggressive, powerful woman may be called “bitch”
 - A man with same qualities considered “ambitious,” viewed with respect
- Adding an HIV diagnosis can magnify this oppression experience
 - 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



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Why Language Matters

- Consequences of HIV-related stigma (from 2005 study) include:
 - Loss of income
 - Loss of hope
 - Increased feelings of worthlessness
 - Increased internalized stigma
 - Poor care in healthcare system, especially from non-HIV professionals
 - Loss of reputation in family and community
- ***Rare to find a woman living with HIV who has not felt stigmatized in some way***



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What Is HIV Stigma Communication?

- The **narrative** (public story of connected events) 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 for stories
 - Emotions most often shared in rumors are fear, anger, or disgust, research shows
- Rumors then become part of our social environment, regardless of whether they are true



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What Is HIV Stigma Communication?

- **Stigma communication** can exist in language, labels, messages used to educate or talk about a health condition or group of people
- Certain medical conditions stigmatized more often than others; seen as moral issues, character flaws, instead of biological diseases
 - 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



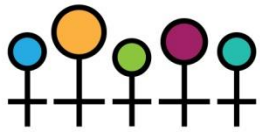
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What Is HIV Stigma Communication?

HIV stigma communication is found in:

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

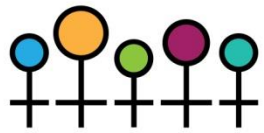
Language we hear (from family or friends, news headlines, research articles, and more) becomes ***language we use*** to describe ourselves and others



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What Is People-First Language?

- Puts person before illness or label
- Describes and respects who they are, not what they happen to have been diagnosed with
- Helps eliminate prejudice; removes value judgments
- Describing people by labels or medical diagnoses devalues and disrespects them as individuals
 - Never hear “cancerous people” or “I am cancer positive”
 - 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

- Document written by HIV advocates in 1983
- In opening words, Denver Principles 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.'**”*
- This narrative 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 HIV or AIDS patient, AIDS or HIV carrier Positives or HIVers	Person living with HIV; PLHIV 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 the term AIDS, or Stage 3 HIV
HIV virus	This is redundant; simply use the term 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, or 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, or life-threatening condition	HIV is a chronic and manageable health condition as long as people are in care and treatment
"Tainted" blood; "dirty" needles	Blood containing HIV; shared needles
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 this term.
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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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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Two Kinds of Stigma

External stigma comes from:

- What we hear from our family, friends, healthcare providers, others
- What we read or hear in media

Internal stigma comes from:

- Self-judgment and **negative self-talk** we hear in our heads
- Developed by our life experiences -- with stigma, discrimination, shame, guilt



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Negative Self-Talk

- Things we tell ourselves daily; define who we are inside
- Sometimes, a story we tell ourselves:
 - We are not good enough, strong enough, smart enough, or 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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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
 - Examining and changing our self-talk



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Mirror Work and Positive Affirmations

- **Mirror work** involves looking in mirror, saying positive **affirmations** (messages we tell ourselves):
 - *"Thank you! That's wonderful!"* when something good happens in life
 - *"This thing will pass, but I love you, and that is forever"* when something bad happens
 - *"Looking good!"* as you look at your own lovely face
- Researchers have found that positive affirmations and mirror work has helped many 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**)
- 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**)



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Examining and Changing Our Self-Talk

Examples of Negative Self-Talk

- I am infected with a horrible disease; no one will love me
- I deserve HIV; it's my fault
- I can't do anything right; I am not good enough
- I am an HIV-infected mother, daughter, woman

Examples of Positive Self-Talk

- I am living with HIV and I am lovable
- I can follow my goals and dreams and live an amazing life
- I am a woman living with HIV and I can empower myself and others



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Changing Language, Making Change

- For many WLHIV, thinking about and make changes to their HIV language has been empowering
- For some, 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
- Some people join campaigns working on language issues
 - HIV advocates have won changes to stigmatizing language used by ***large institutions*** (e.g., U.S. CDC)



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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 anyone questions (even to themselves) use of a phrase that fuels stigma and ignorance, they contribute to building hope
 - This is part of changing our culture from one that disrespects women living with HIV, to one that uses language to support ***power and dignity of all women***



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Learn More!

- To learn more about this topic, and for links to articles featuring more details, please read the full fact sheet on this topic:
 - [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