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Why Language Matters:

Facing HIV Stigma in Our Own Words

Last updated: October 2, 2026

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

#onewomanatatime

www.thewellproject.org

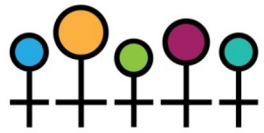
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Why Language Matters

- *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 ***view*** people living with HIV



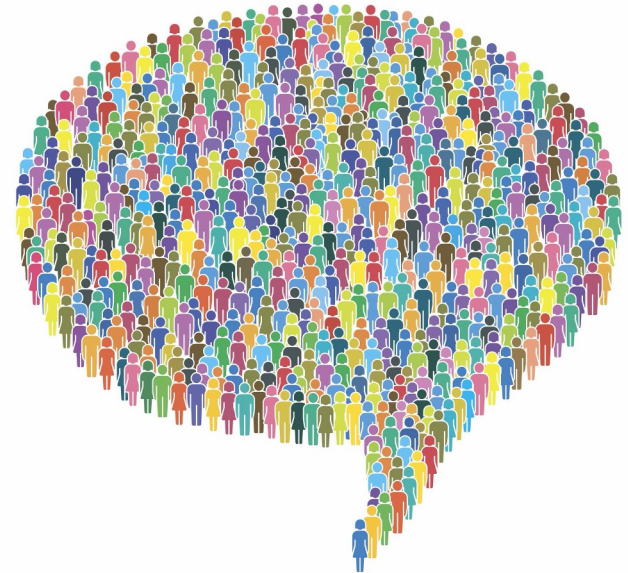
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Words, Language and Perception

- 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



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 outspoken, powerful woman may be called “bitch”
 - A man with same qualities considered “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

Why Language Matters

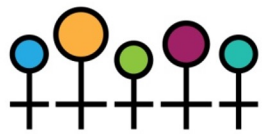
- Consequences of HIV-related stigma (from 2005 study):
 - Loss of income
 - Loss of hope
 - Increased feelings of worthlessness
 - Increased internalized stigma
 - Poor care in healthcare system, especially from non-HIV professionals
 - Loss of reputation in family and community
- ***Rare to find a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

Stigmatizing Language in Healthcare Settings:

Results from The Well Project's Research Among
Women and Nonbinary Adults Living with HIV

bit.ly/HIVLanguageMatters

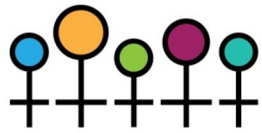




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What Is HIV Stigma Communication?

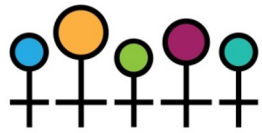
- The **narrative** (public story of connected events) about HIV includes myths and false stereotypes that
 - Stigmatize HIV
 - Isolate people living with HIV
- Stigmatizing stereotypes make for good rumors, gossip
 - News media often use them to get attention for stories
 - Emotions most often shared 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 (“crazy”), substance use (“addicts”; “junkies”), HIV (“infected”)
- Reducing people to a label dismisses their humanity, sets them apart from others



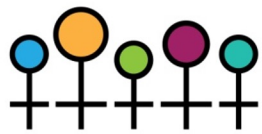
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What Is HIV Stigma Communication?

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



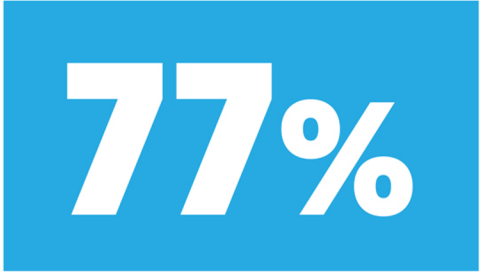
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What Is People-First Language?

- 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

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



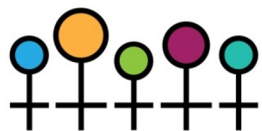
77%

of respondents* (n=166)
agreed that **person-first
language improves
communication and
reduces stigma in
healthcare settings**

bit.ly/HIVLanguageMatters



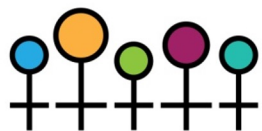
*Respondents include cisgender women, transgender women, and nonbinary adults living with HIV



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Preferred Language About HIV

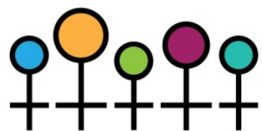
Stigmatizing Language ("Try not to use")	Preferred Language ("Use this instead")
HIV-infected person HIV or AIDS patient, AIDS or HIV carrier Positives or HIVers	Person/people living with HIV <i>Never use "infected" when referring to a person</i>
Died of AIDS	Died of AIDS-related illness, AIDS-related complications, end-stage HIV
AIDS virus	HIV (AIDS is a diagnosis, not a virus; it cannot be transmitted)
Full-blown AIDS	AIDS; AIDS diagnosis; advanced HIV (There is no medical definition for this phrase)
HIV virus	HIV (This is redundant because the "V" in "HIV" already stands for "virus")
Zero new infections	Zero new HIV transmissions or cases



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Preferred Language About HIV

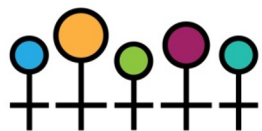
Stigmatizing Language ("Try not to use")	Preferred Language ("Use this instead")
HIV infection(s); became infected with HIV	HIV acquisition(s), HIV diagnosis/diagnoses; acquired HIV, was diagnosed with HIV
Perinatally infected with HIV, vertical	Lifetime survivor of HIV; Dandelion (These are acceptable terms to refer to a person who acquired HIV at birth or early in life, and were chosen by lifetime survivors themselves)
Mother-to-child HIV transmission	Perinatal HIV transmission; vertical HIV transmission
HIV-exposed infant; HIV exposed but uninfected (HEU)	Infant born to a person living with HIV; infant exposed to HIV who did not acquire HIV, infant who was HIV exposed and is HIV free



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Preferred Language About HIV

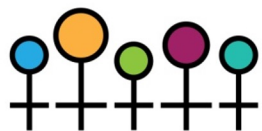
Stigmatizing Language ("Try not to use")	Preferred Language ("Use this instead")
Serodiscordant couple	Serodifferent, magnetic, or mixed-status couple
Victim, innocent victim, sufferer, contaminated	Person living with HIV; survivor; warrior
Catch AIDS, contract AIDS, transmit AIDS, catch HIV	AIDS diagnosis; develop AIDS; contract HIV (AIDS is a diagnosis; cannot be passed from one person to the next)
Compliant	Following their treatment/care plan; taking medication as prescribed; adherent
Prostitute/prostitution	Sex worker/sex work
Promiscuous	Having multiple sex partners ("Promiscuous" is a value judgment and should be avoided)



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Preferred Language About HIV

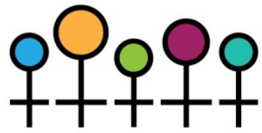
Stigmatizing Language ("Try not to use")	Preferred Language ("Use this instead")
Unprotected sex	Sex without barriers or treatment-as-prevention methods, condomless sex
HIV risk, at risk for HIV	HIV relevance; reasons for HIV prevention; vulnerable to HIV; chance of acquiring HIV; likelihood of acquiring HIV ("Risk" framing focuses on people's individual actions when individual behavior is rarely the driver of a woman's likelihood of acquiring HIV, but rather forces outside women's control: systemic racism, poverty, etc.)
Down-low man; on the down-low	Man who has sex with women and men; bisexual or pansexual man; same-gender-loving man (depends on individual identity) ("Down-low" is a stigmatizing term sometimes used to describe men who may not disclose that they have sex with men as well as women due to stigma against diverse sexualities and sexual practices. Should be avoided)



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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 when people are able to access 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.
"I am HIV"; "I am sick"	"I have HIV"; "I am living with HIV" (HIV is a health condition a person may have; it is not who they are)
End HIV, End AIDS	End HIV transmission, end HIV-related deaths, end the HIV epidemic (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

Two Kinds of Stigma

External stigma comes from:

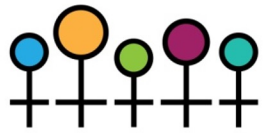
- What we hear from our family, friends, healthcare providers, others
- What we read or hear in media

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

Negative Self-Talk

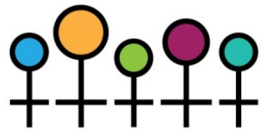
- Things we tell ourselves daily; define who we are inside
- Sometimes, a story we tell ourselves:
 - We are not good enough, strong enough, smart enough, or beautiful enough
 - We deserve everything challenging that has happened to us
 - We are damaged goods
- One of the first places to start to make change is in the ***language we hear in our own heads***



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Empowering Women Through Language

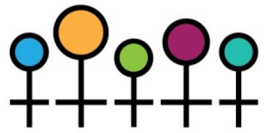
- To address ***internalized stigma***, we can change messages we say to ourselves
 - Helps to change self-image
 - We begin to treat ourselves with more compassion
- Things you can do to make these changes:
 - Mirror work and self-affirmations
 - Examining and changing our self-talk



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Mirror Work and Positive Affirmations

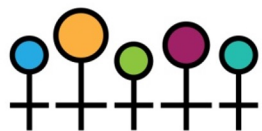
- **Mirror work** involves looking in mirror, saying positive **affirmations** (messages we tell ourselves):
 - *"Thank you! That's wonderful!"* when something good happens in life
 - *"This thing will pass, but I love you, and that is forever"* when something bad happens
 - *"Looking good!"* as you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

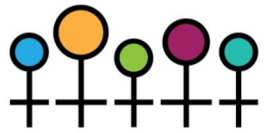
- I am living with HIV, and I am lovable
- I can follow my goals and dreams and live an amazing life
- I am a woman living with HIV and I can empower myself and others



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Changing Language, Making Change

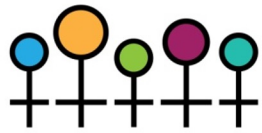
- For many WLHIV, thinking about and making changes to their HIV language has been empowering
- For some, has led to pointing out stigmatizing ***language used by others***: family, friends, providers
- Others may begin ***reaching out to media*** when outlets use inappropriate language
- Some people 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
 - thewellprojecthiv.bsky.social
 - www.facebook.com/thewellproject
 - www.instagram.com/thewellprojecthiv
 - www.threads.net/@thewellprojecthiv
 - www.youtube.com/thewellprojecthiv