

Words MATTER words Matter WORDS MATTER Words Matter words MATTER!



A resource for everyone committed to ensuring all Black people are free – happy, healthy, and whole.

"Words matter in profound and palpable ways"

-David J. Johns

OO OFTEN LANGUAGE IS USED AS A TOOL OF OPPRESSION.

Words and phrases perpetuate stereotypical ideas of individuals or communities of people that shape our views and interactions with each other. Language reinforces the marginalization of individuals through layered forms of oppression and discrimination based on gender, race, sexual identity, socioeconomic status, and other factors. Repeated exposure to this language affirming stigma, oppression, and discrimination affects the health and well-being of an individual.

Words are what we use to process, define, and express our human experience. There is power in precision and words have the power to build or break our perceptions, understandings and expectations. Words can empower or destroy, encourage or discourage, give value or render worthless.

WHY THIS TOOLKIT MATTERS Words Are Tools That Have The Power To Destroy Stigma

Words evolve into the language we use to communicate. Language can be used to create spaces where people feel safe, comfortable, and supported including through personal and difficult conversations. Language is a powerful tool in disrupting bias and stigma as well as facilitating healing.

It is important to eliminate HIV stigma because when people are afraid of experiencing discrimination they are less likely to be tested or treated for HIV. Additionally, treating individuals living with HIV differently can negatively affect their ability to secure life's necessities like housing, employment, medical care, and necessary social support.



Language can be used to create spaces where people feel safe, comfortable, and supported...



The Words Matter HIV Stigma Toolkit is a blueprint cilitating what can understandably be uncomfortable at times, difficult conversations that can save lives.

The toolkit invites each of us to consider three things:

- **1. How do we create safe or brave spaces** where people feel comfortable talking about HIV specifically and holistic health and wellness more generally?
- **2. How does everyday language contribute to stigma** relevant scientific and medical advancements contributing to the disproportionate rate continuing to impact the Black community?
- **3. How can we replace negative and harmful language with affirming and healing language** that has the power to strengthen communities and ultimately end the HIV epidemic?

As a living document, this toolkit will evolve to reflect emerging culturally inclusive practices. The Words Matter Campaign will leverage Black-centered networks committed to the health and well-being of Black communities to disseminate and support the use of the toolkit.





Words Matter Part I : Learning & Unlearning What is HIV Stigma?

HIV stigma refers to negative attitudes and beliefs, prejudice, and discrimination about people living with HIV. HIV stigmatization is a process that builds on previous stigma and discrimination based on actual or perceived health status, race/ethnicity, religion, socio-economic status, age, sex, sexual orientation, and gender identity. Since the beginning of the HIV epidemic, there have been stigmatizing messages and derogatory language towards HIV/AIDS.

Stigma, in part, results from sensational news headlines and prevention messages from health departments, social service and governmental agencies that have misinformed the general public. For example, the phrase "full-blown AIDS" was conjured by the media to evoke the image of something bubbling up inside of a person that might ooze onto someone else who is not living with HIV. There is no such thing as "full blown AIDS," but the clinical term is Stage 3 HIV.

What are the effects of HIV Stigma?

HIV stigma affects the well-being of people with HIV. People living with HIV often internalize the stigma they experience and being to develop a negative self-image. They may fear they will be discriminated against or judged negatively if their HIV status is revealed.

"Internalized stigma" or "self-stigma" happens when a person takes in the negative ideas and stereotypes about people living with HIV and start to apply them to themselves. HIV internalized stigma can lead to feelings of shame, fear of disclosure, isolation, and despair. These feelings can keep people from getting tested and treated for HIV.



Examples of HIV Stigma	Examples of Discrimination	Effects of HIV stigma and discrimination
1. Belief that only certain communities get HIV	1. Health care professional refusing to provide services to someone living with HIV	 Increased internalized stigma Decreased participation in
2. Feeling that people deserve to get HIV because of their choices	 Prosecuting people living with HIV for failing to provide proof 	preventative measures 3. Marginalized treatment in health care
3. Judgement of those who take steps to prevent HIV transmission or treat HIV	of disclosure HIV status to partner and employers	4. Loss of family and/or community
	3. Refusing casual or intimate contact with someone living with HIV	 Increased stress Loss of income
	4. Socially isolating an individual or a community because they	

are living with HIV

Stigma Terminology Guide

Use this guide to inform positive, Asset-based communication

Stigmatized language to avoid	Explanation	Preferred language
HIV patient, AIDS patient	People-first language puts the person before the medical condition.	Person living with HIV
Positives or HIVers	It describes the condition they have, not who they are and consequently honors	
AIDS or HIV carrier	their humanity.	
Clean	<i>This term implies that individuals living with HIV are "dirty".</i>	HIV-negative
<i>Died of AIDS, to die of AIDS</i>	AIDS is not an infectious agent- it is a surveillance definition meaning a syndrome of opportunistic infections and diseases that can develop as immunosuppression deepens along the continuum of HIV infection.	<i>Died of AIDS-related illness, AIDS- related complications or end stage HIV</i>
AIDS virus	AIDS virus is non-existent. AIDS is a syndrome, not a virus.	HIV
Full-blown AIDS	This implies there are varying stages of AIDS like half-blown AIDS. People have AIDS only when they present with AIDS-defining illness like an opportunistic infection. (Give media context)	There is no medical definition for this phrase, simply use the term AIDS, or Stage 3 HIV.
HIV virus	This term is redundant. HIV stands for Human Immunodeficiency Virus.	HIV
AIDS orphans	Mislabels children as HIV-positive. Stigmatizes an individual based on social condition.	Orphans and other children made vulnerable by AIDS
HIV infected mother	Mislabels individuals. Stigmatizes an individual based on medical condition.	Mother living with HIV
Mother to child transmission	Results in blaming mothers	Vertical transmission, perinatal transmission

People-first language puts the person before the medical condition.



Stigmatized language to avoid	Explanation	Preferred language
AIDS test	AIDS is not a virus; therefore, there is no test for it.	HIV test
<i>To catch AIDS To contract AIDS To catch HIV</i>	AIDS cannot be caught or transmitted. People can be exposed to and contract HIV.	An AIDS diagnosis, to contract HIV
To pass on HIV	HIV can be transmitted, not inherited	Transmit HIV
Prostitute or prostitution	<i>"Prostitute" is a disparaging word that does not reflect that sex work, for some, is a form of employment, not a lifestyle.</i>	Sex worker
Promiscuous	<i>This term is derogatory, judgmental, and accusatory.</i>	This is a value judgment and should be avoided. Instead Use - Having multiple partners
Down-low	This term has been used, chiefly by the media, to label subgroups of Black men who engage in same-sex behavior associated with sexual risks for HIV transmission in Black communities.	Do not use this to describe individuals as it is derogatory and continues homophobia, biphobia, and LGBTQ/SGL bias and stigma.
Thot	This is a derogatory acronym for "that hoe over there" or "thirsty hoe over there" suggesting one is sexually promiscuous.	Do not use this to describe individuals as it is misogynistic and derogatory.
In these streets	Another term to describe individuals' sexual history as promiscuous.	Do not use this to describe individuals as it is derogatory.





HIV in the Black Community

- 1. Black Americans account for a higher proportion of new HIV diagnoses, those living with HIV, and those who have ever received and AIDS diagnosis, compared to other races/ethnicities.
- 2. In 2016, Black Americans accounted for 44% of HIV diagnoses, though they compromise 12% of the U.S. population.
- 3. Gay, bisexual, and other men who have sex with men (MSM) account for 70% of new HIV infections in our nation, with Black gay, bisexual, and other MSM making up the majority of these new infections annually.
- 4. Black gay and bisexual men tend to have sex partners of the same race which lend to smaller sexual networks with more partners living with HIV increasing the chance of coming in contact with HIV, compared to white or Hispanic/Latino gay and bisexual men.
- 5. Limited access to quality health care, lower income and educational levels, and higher rates of unemployment and incarceration may place some Black Americans, like gay, bisexual men, and transgender women, at higher risk for HIV.
- 6. Between 2012-2015, only 10% of all new PrEP prescriptions were made for Black/African Americans
- 7. Stigma, discrimination, homophobia put those at risk for HIV in Black America at risk for many health issues and may affect their ability and access to quality health care, which serves as another barrier to eradicate HIV/AIDS in Black America.

To move closer toward eliminating HIV viral transmission, we must:

- 1. Increase the number of Black people getting tested;
- 2. Reduce the numbers of Black people becoming HIV positive;
- 3. Increase support for Black people living with HIV, including prioritizing the suppression of viral loads;
- 4. Educate the general public on how language can stigmatize people living with HIV and thereby, decreasing the number of people affected by HIV;
- 5. Provide culturally inclusive language to curate conversations on the impact of HIV on their communities; and
- 6. Raise awareness of the disproportionate impact of HIV/AIDS in Black communities.





Words Matter Part II : The Discussion Community Conversations

Community conversations are about cultivating meaningful discussions rooted in empathy, understanding, vulnerability, and humanity. These conversations are intentional, thus we take the time to hear and understand all point of views without jumping to conclusions. It is our hope that you walk away feeling heard and empowered.

HIV/ AIDS Words Matter toolkit is a roadmap to help facilitate community conversations, authentic exchanges, that bridge the gap between stigma and language. Use the instructions below to help guide your community conversation, both informal or formal.

INSTRUCTIONS

Step 1: Prepare for Conversations by centering and grounding. Take the time to breathe together before engaging in an internal body scan, which helps to track what is happening in your body that has the potential to shape the conversation (e.g. moods, thoughts, anxiety, and energy).

Step 2: Identify Guiding Principles

Use guiding principles to maintain shared expectations throughout the conversation.

1. *Intentionality*: Remember, words matter. Be intentional with language. Begin by discussing and committing to respect names and pronouns. Avoid language that is intended to harm and be mindful of bias that may be reflected in your words and how you communicate them.

If you do not feel that you have the language needed to communicate a particular feeling or express a point come from a place of love and also consider asking for assistance in finding the language that comes closest to communicating how you feel.

- 2. **Respect**: Expect varying perspectives. Respect everyone participating in the conversation by investing your energy in understanding rather than judging or listening simply to respond.
- **3.** *Mindfulness*: Be and stay present and aware of who is speaking and what they are saying by giving them the gift of your full attention. Actively listen without interrupting. When the person is done speaking, reflect what you heard them say before sharing your thoughts and feelings.
- **4. Open mind**: Expect to be made to feel uncomfortable as you learn and grow. Keep an open mind and commit to learning.



Community conversations are about cultivating meaningful discussions rooted in empathy, understanding, vulnerability, and <u>humanity.</u>

The Power of Pronouns

Use this chart as guidance to pronouns. This list is NOT exhaustive. Any pronouns are valid!

Note: As the facilitator, introduce your pronouns to model for the other members of the conversation. Explain why you're saying your pronouns and invite others to introduce their pronouns. If someone does not want to disclose their pronouns, refer to that person by their name.

When my pronouns are:	Use them in this way
She, her, hers	She had great insight. Her authenticity is admirable. I support her in the conversation by honoring her pronouns.
He, him, his	He has so much passion! His feelings are valid. I support him in the conversation by honoring his pronouns.
They, them, their	They are understanding. Their presence makes me feel safe. I support them in the conversation by honoring their pronouns
Ze, zir, zirs	Ze is courageous. I have learned so much from zir. I support zir in the conversation by honoring zirs pronouns
Ze, hir, hirs	Ze is kind. I love hirs perspective. I support hir in the conversation by honoring hirs pronouns

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Step 3: Stimulating Conversation:

The following activities are designed to help advance meaningful conversations about stigma.

ESTABLISH INTENT

Answer these questions together:

- 1. Why did you want to engage in this conversation?
- 2. What do you hope to accomplish as a result of having engaged in this conversation? What will happen after the conversations concludes?
- 3. What do you not know that makes you uncomfortable or anxious?
- 4. What do you know or feel that you want to ensure is understood or considered?

Answer these questions individually:

- 1. What is your definition of stigma or bias?
- 2. How does feeling silenced or experiencing bias make you feel?

Anticipated responses:

- a. This makes me feel.....
- b. It makes me think of doing.....
- 3. How do I react when I witness stigma or bias?
- 4. How do I want to reach when I witness stigma or bias?
- 5. How does stigma or bias manifest in my language and communication?
- 6. What steps will I take to ensure that stigma and/or bias does not manifest in my language or communication?

We can advance meaningful conversations about stigma by being intentional and respectful.



Naming Stigma Through Pictures

This activity is from <u>Facilitator's Training Guide for a Stigma-Free Health Facility</u> and <u>Understanding</u> and <u>Challenging HIV Stigma'' Toolkit for Action</u>. A complete set of images for discussion is on the site.



1. Name the form(s) of stigma reflected in each picture:

Forms of stigma

- a. **Isolation and Rejection** Based on ignorance and fear about HIV transmission or behaviors of a marginalized group. The person stigmatized is forced to sit alone and others avoid casual or intimate contact with them.
- b. **Shaming and Blaming** Gossip, name calling, insulting, judging, shaming. Stigmatized people are "blamed and shamed" for assumed "bad behavior", i.e. for breaking social norms.
- c. **Discrimination (Enacted Stigma)** Unfair treatment, such as refusing to provide health services to people living with HIV and high risk populations, treating them last, or testing clients without their consent.
- d. Self-Stigma- People living with HIV or key populations may stigmatize themselves in reaction to stigmatization from society. They may accept the blame and rejection of society, and withdraw from social contact or exclude themselves from accessing health and other services out of fear of having their status revealed.
- e. Stigma by Association- The families of people living with HIV or key populations may be stigmatized by others in the community. Some health workers are also stigmatized for working with people living with HIV or key populations.
- f. Layered Stigma (intersectionality) Key populations (e.g. sex workers, gay and bisexual men, transgender individuals, people who use drugs, people in prison) are already stigmatized. When living with HIV, they are doubly stigmatized- adding another layer of stigma.
- 2. What do you think is happening and why?
- 3. What stereotypes or narratives inform understandings or readings of the images/pictures?
- 4. Is the stigma/bias depicted reflected in your life or community? If so, give examples. If not, why not?
- 5. How does this make you feel? Why?
 - If you do not register particular feelings, why do you believe this to be the case?

Thought-Provoking Questions

- Read the domains and questions aloud, in pairs, or individually.
- After each question, allow time for each person to write/record their thoughts (within 2 minutes):
 - **1. Domain: Fear of Infection**. Do you fear that you could contract HIV if you come into contact with the saliva of a person living with HIV?
 - 2. Domain: Social Judgement. Do you agree or disagree with the following statement: I would be ashamed if I or someone in my family had HIV.
 - **3.** Domain: Legal and policy environment. Is there a law that prosecutes/criminalizes those who do not disclose their HIV status to partners and employers in your state?
 - Is there a law that protects LGBTQ/SGL individuals in your state?
 - What public policies help to prevent HIV and also provide access to treatment for people living with HIV?
 - **4. Domain: Anticipated Stigma**. In your opinion, are people hesitant to take an HIV test due to fear of people's reaction if the test result positive for HIV?
 - 5. Domain: Perceived Stigma. Do people talk badly about living with or thought to be living with HIV to others?
 - Do people living with or thought to be living with HIV lose respect or standing?
 - 6. Domain: Experienced Stigma (outside of legal perspective). Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person was living with HIV?
 - 7. Domain: Experienced Stigma (inside legal perspective). Do you think children living with HIV should be able to attend school with children who are HIV negative?

Note: These questions were adapted from the 'General Population' column of Measuring HIV stigma and discrimination chart.



Media Analysis

Use multimedia (movies, television shows, songs, podcasts, etc.) that have positive and affirming approaches to centering HIV/AIDS topics to spark conversation.

• Watch and discuss films like *Tongues Untied*, *Life Support*, and *90 Days*:



• Engage with the Positive Spin series (https://positivespin.hiv.gov/)



After viewing/engaging with media, answer together:

- 1. What happened?
- 2. How did the characters feel and why?
- 3. What stereotypes or bias inform beliefs and practices employed?
- 4. How do you feel about what sharpened and why?
- 5. What support systems were in place for the characters and why did they matter?
- 6. How do the experiences in the film relate to your personal experiences?
- 7. What would you change, how and why?

Reflect on personal experiences with stigma

Disclaimer: Please note that speaking on making changes to agents of stigma might bring up trauma or a painful memory and that participants are not required to participate or share that trauma.

This activity was adapted from

Understanding and Challenging HIV Stigma: Our Experience As Stigmatizer.

• Individually reflect.

- Write about a time in your life when you felt isolated or rejected for being perceived as different and answer the question: **How did you feel when you were stigmatized?**
- Write about a time in your life when you isolated or rejected someone for perceiving them as different and answer the question: What thoughts, feelings, or words do you associate with stigma?
 - What stops you as a conduit of change?
 - What beliefs, philosophies or lived experience could influence the way in which I perpetuate stigma?

• Invite everyone to share their stories to the group.

- Answer as a group:
 - What common language was used in the experiences we had being stigmatized and stigmatizing others?
 - What language should not be used going forward and why?
 - What language should replace problematic language or otherwise be used to support additional conversation?

• Close the Discussion

- Each person should answer these questions to the others:
 - What did you learn from this discussion?
 - What will you do differently the next time you talk to someone about HIV?



ADDITIONAL RESOURCES:

- 1. <u>HIV 101</u>
- 2. Understanding and Challenging HIV Stigma
- 3. <u>Facilitator's Training Guide For A Stigma-Free</u> <u>Health Facility</u>
- 4. Positive Spin Facilitator's Guide
- 5. Measuring HIV Stigma and Discrimination
- 6. Positive Women's Network USA



Words Matter Part III : Get Involved Take The Pledge

Download the digital pledge card and share with your community why your #WordsMatter

As an active member of my community, I will stand up to erase HIV stigma to highlight the importance of cultural competence. We believe to create spaces where people living with HIV feel empowered, supported, and free from shame lies in the power of our words and thoughts.

I Pledge to do the following:

- **1. Be Informed.** I commit to avoid using using derogatory and harmful words that perpetuate HIV/AIDS and LGBTQ/SGL stigma.
- **2. Be an Advocate.** I will engage in courageous community conversations with family, friends, support groups, elected officials or co-workers to destroy stigma and increase HIV prevention, treatment and support. I will talk to my elected leaders and ensure they advocate for culturally competent and inclusive policies and practices.
- **3. Spread the Word.** I will share the HIV/AIDs toolkit and Words Matter campaign using the hashtags #YourWordsMatter #EndHIVStigma #StartTalkingStopHIV
- 4. I will get tested regularly and encourage those I know and love to do the same.



Get Tested

YOU SHOULD GET TESTED FOR HIV AT LEAST EVERY SIX MONTHS.

Need help finding somewhere to get tested? Visit <u>HIV Testing search tool</u> to find testing services in YOUR local community.

You can also find an HIV testing location near you: **TEXT YOUR ZIP CODE TO "KNOW IT" (566948) CALL 1-800-CDC-INFO**



Legislative Advocacy

TALK TO YOUR PUBLIC OFFICIALS.

Familiarize yourself with HIV criminalization statutes in your state and engage your public officials that have the power to repeal these stigmatizing laws. In addition, make sure your elected leaders on all levels of government are working to ensure that all people have access to quality and affordable health care, especially people living with HIV and other pre-existing conditions like diabetes and hypertension that disproportionately impact Black people. In order to end the epidemic, we must change our culture in our communities, but we must also be leading efforts to ensure our government is advancing public policies that support our collective health and wellness.

MEETING WITH LEGISLATORS & OTHER PUBLIC OFFICIALS

WHY ADVOCATE?

The best public policy in the world isn't going anywhere if it's not supported by human relationships based on repeated interactions."

- Many people don't dedicate this kind of time and energy to a cause, or travel to Washington or local offices to meet with their elected officials.
- Your voice is heard, especially if you are a voter in a legislator's district or state.
- It's the most likely thing to change the mind of a Member of Congress. ("Policy influence" ratings: #1 meeting a constituent, #2 other lobby/advocacy visits, #3 personal phone calls, #4 personalized letter or email, #5 Letter to editor, #6 post-cards or petitions)

It takes effort, demonstrates high level of commitment to a cause.

Your voice is heard, especially if you are a voter in a legislator's district or state.



Legislative Advocacy

PREPARATION FOR MEETING

- Know about your federal senator or representative: positions on key issues, committee assignments.
- www.govtrack.us: provides basic information on Members of Congress, voting records, etc. as well as links to useful other websites such as CommonSense and OpenSecrets
- http://capwiz.com/fconl/directory/congdir.tt Friends Committee on National Legislation website for background on Members' votes, staffers, PAC's, committee assignments.
- League of Conservation Voters: www.lcv.org/scorecard
- Know the issue. Be able to state reasons for your own position (and read what your opponents say to prepare)
- www.govtrack.us: recent bills on the issue
- Go to organizations who work on your issues
- Plan your speaking roles. Decide ahead of time who will say what. Better not to have more than 4-5 people speak during a meeting with your legislator and/or their staff. You can bring more for support make sure you know how many can fit in the office.
- Many times a legislator or public official may designate one of their staffers to meet with you for a scheduled meeting. That's OK! They will convey your views to their boss and if you develop a good relationship with the staffer you have a better chance to influence the official's decisions or votes on issues like supporting the repeal of HIV Criminalization laws or access to healthcare.
 - **NOTE:** On the state and local level these general principles are effective for meeting with your elected officials.
 - **NOTE:** Visit www.sero.com to find who in your state is doing the work to change the laws and visit www.chlp.org to find updated studies and other resources on laws around the nation.



Legislative Advocacy

YOU CAN'T GET WHAT YOU DON'T ASK FOR

- Know what you want to get out of the meeting. Most important: ALWAYS HAVE AN ASK!
- Asking provides real accountability, AND something to follow up on.
- Clearest asks are usually to vote a certain way or to or cosponsor a bill. That is advocacy in action.

OUTCOMES

- You may not get an answer, and that's ok. Follow up on the ask if it was specific.
- Staff person may not feel comfortable speaking on behalf of the legislator, but will convey information.
- If you don't have an answer to a question of theirs, that's ok too. It's your opportunity to follow up.
- It's all about follow-up. It's an ongoing process. You don't clinch the deal in one meeting.

FOLLOW-UP

- Send a thank you note and include the ask one more time.
- If you promised information, send it ASAP.
- Send information that would be useful to your legislator at least four times a year.
- Follow up every contact with a phone call.
- Be helpful, keep it friendly. Remember: It's all about building a relationship.

If you remember nothing else remember the following: you are the expert and the boss when engaging with your elected official or their staff. You know best how your elected officials can support you, your family and communities at-large. Visits or other opportunities to engage with your elected officials (E.g. letter writing campaign, call office to voice opinion, community debates) are an opportunity for you to meet the leaders who serve the represent you and those you love. Consider this an opportunity to accomplish two important goals: 1) develop and strengthen relationships with elected leaders and their staff and 2) an opportunity to discuss legislative policy priorities like advancing public policies that empower people living with HIV and those impacted by HIV in their communities.

If you remember nothing else remember the following: you are the expert and the boss when engaging with your elected official or their staff.

Stay Engaged

CONNECT WITH US DIGITALLY

To demonstrate your support for the #WordsMatter campaign please post tailor the following content to suit your voice and personality. Be sure to include #YourWordsMatter, #EndHIVStigma and #StartTalking where possible so we can find and share your messages!

CAMPAIGN HASHTAGS:

Please use the following hashtags when posting on social media about the importance of #Words Matter

#YourWordsMatter #EndHIVStigma #StartTalkingStopHIV

SAMPLE TWEETS/INSTAGRAM CAPTION MEDIA POSTS:

- Too often language is used as a tool of oppression. We have chance to #EndHIVStigma because I know #YourWordsMatter
- Words Are Tools That Have The Power To Destroy Stigma. #EndHIVStigma #YourWordsMatter
- #StartTalkingHIV because #YourWordsMatter when you talk to partners and friends about HIV.
- #YourWordsMatter to your partners and friends. Let's have a conversation to #EndHIVstigma.
- "Oppressive language does more than represent violence; it is violence; does more than represent the limits of knowledge; it limits knowledge." -Toni Morrison #YourWordsMatter
- "I have come to believe over and over again that what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised or misunderstood. – Audre Lorde" #YourWordsMatter





#YourWordsMatter

#EndHIVStigma

#StartTalkingStopHIV

