

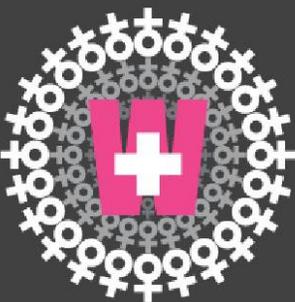


POSITIVE WOMEN'S NETWORK
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Five Things Media Makers Can Do NOW to Stand Up to HIV Stigma

- 1. Watch Your Language!**
- 2. Put the “Living” in “People Living with HIV”**
- 3. Talk to Women Living with HIV**
- 4. There Are Facts and Fictions About HIV. Choose Facts.**
- 5. Write About HIV Disclosure as the Complicated Issue it Is**



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Five Things Media Makers Can Do NOW to #StandUpToHIVStigma

Mainstream reporting on issues concerning HIV is often [sensationalized and stigmatizing](#), sometimes doing more harm than good. In fact, warned [Josh Barro last year on MSNBC](#): “Negative attitudes about HIV are literally killing people.” Within the HIV community, this is widely known and well documented: [Stigma](#) fuels the HIV epidemic by creating barriers to HIV testing and care access, and by placing people with HIV at risk for discrimination and violence.

But the responsibility for addressing and ending HIV stigma cannot rest on people living with HIV alone. Makers of mainstream media have a responsibility to stop using language that labels and “others” people with HIV and communities at risk for HIV. According to a Kaiser Family Foundation survey, [62 percent of people in the US get their HIV information mainly from media](#). By becoming informed about the realities of living with HIV and incorporating these facts and stories into their reporting, **media makers can also be some of our greatest allies** in improving lives and upholding rights for people with HIV.

So, in the spirit of allyship – and helping media makers satisfy their professional responsibility to [seek and report truth](#), Positive Women's Network-USA (PWN-USA), a national membership body of women living with HIV, offers this primer for media makers to start today - right now! - to become allies in eliminating HIV stigma, one article and one report at a time.

To view this statement online, go to: pwnusa.wordpress.com/media/five-things-stand-up-to-hiv-stigma/

Special thanks and deep gratitude to all the insightful PWN-USA members who acted as Co-Authors and Contributors to this statement:

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1. Watch your language!

The stigma attached to HIV is a significant barrier to *living well* with HIV. By working together, we can raise awareness and help improve the lives of those living with HIV by being mindful of our language. Language can be a tool to empower, or to further stigmatize. Media messages can support HIV prevention, care, and treatment by using empowering, appropriate terminology:

- a. *Refer to those living with HIV as "people living with HIV."* Always put the person before the disease. We are people first – we are not our disease.
- b. *Use "diagnosed with" or "acquired" HIV, instead of "infected with" HIV or "HIV-infected."*
- c. *Avoid words designed to shame or judge people – for example:*
 - "promiscuous" to describe a person who has had multiple sex partners is a judgmental term and is often applied differently to heterosexual men, gay men, and women.
 - ["prostitute" to identify a sex worker](#) – the former is a legal term that does not apply in every context; the latter is preferred.
 - "clean" or "dirty" when referring to HIV status. Clean and dirty should only be used when referring to laundry and dishes, not people.
- d. *AIDS is a diagnosis and not a disease* – understand the differences between HIV and AIDS. People cannot transmit AIDS. AIDS is not a virus. [Read a detailed definition of "AIDS"](#) (from The Well Project)
- e. *Refrain from using the term "full-blown AIDS."* This term is still used by many media outlets – but **there is no such thing as full-blown AIDS**. The term is "[antiquated, redundant, stigmatizing and confusing](#)," as one longtime HIV provider put it. Replace with "an AIDS diagnosis" or simply "AIDS."
- f. Apply the information above and below to headlines, the gateway to stories – and *avoid sensationalist headers* such as "AIDS-Positive Alabama Pastor Who Slept with Congregants Banned from Church," from the Associated Press last October.

[View the full slide set for the webinar](#) "Eliminating Stigma from the Language of HIV Communications" - or [view a recording of the full webinar](#) including slides and voices of presenters



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Replace these terms With these preferred terms
HIV positive, positives or <u>HIVers</u>	Person/people living with HIV
AIDS or HIV carrier	
HIV patient, AIDS patient	
Infected with HIV	Diagnosed with HIV; acquired HIV
Catch AIDS Contract AIDS	Receive an AIDS diagnosis; develop AIDS
Full-blown AIDS	AIDS; an AIDS diagnosis
Clean or dirty	<u>Do Not Use</u>
Victim	<u>Do Not Use</u> when referring to a person with HIV - or the sex partner of a person with HIV
Prostitute or prostitution	Sex worker; sale of sexual services
Promiscuous	Having multiple partners



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2. #WeAreAllPeople: Put the “Living” in “People Living with HIV”

From the beginning of the epidemic, HIV in the US has been perceived by some people as a moral issue and not a human one. People with HIV need the media to recognize, report, and share our stories as the mothers, fathers, sisters, brothers, aunts, uncles, neighbors, and grandparents that we are.

More often than not, those of us who are **people living with HIV** are framed in media as monsters, infected, dirty, predatory, and more. Those who are reported as having acquired HIV – or having been intimate with a person with HIV – are labeled as victims or as having been preyed upon. In truth, people living with HIV are just that: people. HIV is the human immunodeficiency virus that attacks the CD4 cells within a **PERSON**. And many of our partners choose to be with us because they love us and it is not “risky” to be intimate with us.

HIV is no longer the “death sentence” it was once thought to be. It is a chronic illness that can be managed with proper care and medication. Today, **people** living with HIV are doing just that and beyond; they are thriving. The life expectancy of a **person** living with HIV who takes medication is [about the same in the US as those who are negative](#).

When reporting on a story, it is crucial that media makers actually talk to a person living with HIV in order to get an accurate reflection of life beyond the diagnosis of HIV. It is a common occurrence that most people did not educate themselves about HIV until they received a diagnosis. They are not at fault. Many people who acquired HIV state they never believed it could happen to them – *in part because messages received through media imply that people living with HIV are somehow different from those who are not, when HIV status is the only difference.*

Therefore:

- a. Coverage of people living with HIV should highlight accomplishments and achievements that are not focused on the virus.
- b. Stories of people living with HIV should include our strength, survival, and courage.
- c. The media could promote the importance of ending stigma, to create environments safe for knowing one's status, HIV testing, and open communication with partners.



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3. HIV is not just a man's issue; it never has been. *Talk to women living with HIV.*

We, women living with HIV, articulate truth that must not be distilled. While living with HIV, we work, raise families, cook, help aging parents, bear children, march, protest injustices, lead the way at conferences, fall in love, and empower each other.

Women account for at least a quarter of people living with HIV in the US, and more than half of all people with HIV worldwide. This makes us the overwhelming experts. We stand bold, as in front-page news. We are not the stuff of margins.

[African-American women were 64% of all women diagnosed with HIV](#) at last count, in 2010. A third of transgender women in the US are living with HIV; the majority of transgender women diagnosed with HIV are women of color. If you are not engaged in conversations about HIV with women of color, you are really missing the point. You may be missing the whole truth, the undisputed truth, the unadulterated story of HIV in the US.

Resources for finding women's stories:

- **Positive Women's Network – USA (PWN-USA)** www.pwn-usa.org – Features a wide variety of advocacy resources for women with HIV, including opinion pieces and statements highlighting the perspectives and expertise of women advocates living with HIV.
- **International Community of Women Living with HIV (ICW)** <http://www.icwglobal.org/> - The only global network by and for women with HIV; features stories of women living with HIV around the world.
- **The Well Project** <http://www.thewellproject.org/> - Features cutting-edge information, personal reflections, and research tailored for women with HIV.
- **TheBody.com's Women's Resource Center** www.thebody.com/women - Features first-person stories and videos by women living with HIV, as well as basic information about women and HIV.



4. There are facts and there are fictions about HIV. Choose facts.

It is ridiculous that, more than 30 years and loads of research and lived experience into the HIV epidemic, we continue to encounter and fight the same myths and misinformation about HIV, in newspapers and on TV as well as in our daily lives.

Three key facts to remember:

- a. **[HIV can only be transmitted through four body fluids getting into the body in very specific ways.](#)** The fluids that are capable of containing high concentrations of the virus – blood, semen, vaginal and rectal secretions, and breast milk – must come in direct contact with a mucous membrane or damaged tissue or be directly injected into the bloodstream (from a needle or syringe) for transmission to be possible. HIV transmission is *not* possible, under any circumstances, through a hug, a handshake, a toilet seat, sharing a cup, or [eating food cooked by a person with HIV](#). Period. The fact that these myths persist in the general population is damaging to the wellbeing of people with HIV, and shows how great the need is for reporting on HIV that is not only accurate, but that actively counters misinformation.
- b. **[People living with HIV can have HIV-negative babies.](#)** Now more than ever, women and men living with HIV are exercising their reproductive rights, and adding to their biological families. A baby born to a woman living with HIV has [less than a 1% chance of acquiring HIV](#) during pregnancy or birth if the baby's mother has access to proper care and treatment. And if one partner in a couple is not living with HIV, the best prevention tool yet is for the partner who's living with HIV to be on successful treatment. Then risk of transmission to the partner drops to virtually zero, even when having sex without condoms. (Read more about that excellent and no-longer-new news [here](#) and [here](#)).
- c. **[Laws that criminalize HIV-positive status do not protect or help women.](#)** As of this writing, 32 states and two US territories have HIV-specific laws that attach criminal penalties to the behavior and actions of people living with HIV. These laws are often framed in the media as protecting women "victims" from dishonest partners, but the laws help no one. These laws codify stigma, and actually deter people from getting tested or being in care (a person who doesn't know their HIV status cannot be prosecuted for HIV nondisclosure or exposure), thereby hindering public health solutions. In most HIV-related prosecutions, [no transmission of HIV even occurred](#)! Further, women have been sent to prison under these laws, and/or had their children taken away for no reason – often by partners who knew the woman's HIV status but used the laws as a tool of abuse, coercion, or harassment when the woman attempted to end the relationship. Making it a crime not to disclose HIV-positive status should never be framed as the answer to addressing HIV in communities or to keeping people HIV negative.



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5. A person's choice to tell someone their HIV status is complicated. Write about HIV disclosure as the complicated issue it is.

Telling another person, especially a potential partner, that you're living with HIV is extremely complex, and not disclosing is *never* simply about "selfishness" or intent to harm – emotionally or otherwise.

Important points to keep in mind when reporting on HIV nondisclosure:

- a. **Simply saying "I'm HIV positive" is not always a safe option.** The very real threat of intimate-partner violence may keep a woman from telling a partner she is living with HIV. The cases of [Cicely Bolden and Elisha Henson, murdered in Texas due to their HIV status](#), are two devastating examples of this reality. Because of stigma and discrimination, disclosure may also place a person at risk for losing their employment, childcare provision, and more. Further, in the presence of laws that penalize people with HIV for knowing their HIV status, disclosing won't protect a woman in a he-said-she-said argument in court, where the person who knows their HIV-positive status usually loses. Women are often the first person in the relationship to be aware of their HIV-positive status.
- b. **Preventing the transmission of HIV is each partner's responsibility, not solely the partner who's living with HIV.** But unequal power dynamics in relationships, among other factors, can block the ability of *either* partner – whether living with HIV or not – to take action to prevent HIV. In many relationships, negotiating use of condoms or other prevention options may be difficult or even impossible. One answer to empowering individuals in their relationships and fostering healthy, safe communication is to [address the root causes of inequities that impact our lives and relationships, and drive the HIV epidemic](#) - and to ensure comprehensive, medically accurate sex education. The solution is not to blame people for having HIV, or cast their sexual partners as "victims." Where there is a victim, there must be a perpetrator, and having HIV is not a crime.
- c. **HIV stigma does not operate alone;** for many women of all gender identities living with HIV in the US, other stigmas – based on race, class, gender expression, sexuality, ability, or other factors – were likely already a part of life before acquiring HIV, and exacerbate HIV stigma after diagnosis. Any trait that sets a person apart from a societal norm can be challenging to talk about, or to disclose. HIV status is no different.
- d. **It is the right of all cisgender and transgender women, including women living with HIV, to be sexual beings.** A key aspect of internalized stigma for many women with HIV is being cut off from their right to safe, pleasurable, intimate relations. When journalists convey messages that shame the sexuality of people with HIV in their



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reporting – as if to even be having sex as a person with HIV is somehow wrong – or imply that finding love, having sex, or being in relationships is impossible for people living with HIV, they validate that assumption. A healthy dose of nonjudgmental sex-positive messaging in mainstream media could save and improve lives.

- e. **Everyone who is living with HIV has a story of how they acquired HIV.** It is a part of a person's history, and does not have to involve a "victim" and a person "at fault."

How a journalist reports on a story can determine the way the story is received – and the tone of comments people leave. A more humanizing, less oppositional approach to reporting on disclosure could foster more civil, less reactionary online discussion around challenging, and potentially unifying, topics like HIV.

BONUS: Consult community resources like the ones referenced above, and in the list below!

AIDSmep.com – Independent, clear and accurate information about HIV

AIDSMeds.com – Quality information about HIV treatment and care

AIDS United – A wide variety of HIV resources

AIDS.gov – Federal resources as well as basic information about HIV

HIVPlus Magazine – Online home of the community news magazine (HIVPlus has also developed a brief, helpful guide for journalists covering HIV)

Kaiser Family Foundation – Provides trusted information on national health issues, including HIV

POZ Magazine – Online version of the longtime print publication

Sero Project – A network of people living with HIV and allies fighting for freedom from stigma and injustice, and opposing HIV criminalization

TheBody.com – The most comprehensive HIV news, information, and support resource on the Web