



# GETTING TO ZERO ILLINOIS STYLE & MESSAGING GUIDE

CREATED BY THE GETTING TO ZERO ILLINOIS COMMUNICATIONS COMMITTEE

## INTRODUCTION

The goal of the Getting to Zero Illinois (GTZ-IL) style and messaging guide is to ensure that those connected to the GTZ-IL initiative and those seeking to support the community are using non-stigmatizing and accurate language, messaging and imagery when referring to community members and our work.

This guide was created by the GTZ-IL communications committee and is a living document that is subject to change as language evolves. The GTZ-IL communications committee is responsible for updating this content as necessary, so please reach out to **Bailey Williams** ([bwilliams@aidschicago.org](mailto:bwilliams@aidschicago.org)) for any recommended updates or content submissions.

**TABLE OF CONTENTS**

INTRODUCTION ..... 1

TABLE OF CONTENTS ..... 2

STIGMATIZING LANGUAGE v. NON-STIGMATIZING LANGUAGE ..... 3 – 4

EMPOWERING IMAGES OF COMMUNITY MEMBERS ..... 5

PEOPLE-FIRST v. IDENTITY-FIRST LANGUAGE ..... 6

COMMUNITIES & IDENTITIES ..... 7 – 9

ADDITIONAL TERMS & CONCEPTS ..... 10 – 11

GETTING TO ZERO ILLINOIS MESSAGING AND TALKING POINTS..... 12 – 13

SOURCES ..... 14

**STIGMATIZING v. NON-STIGMATIZING LANGUAGE**

<b>Stigmatizing</b>	<b>Non-stigmatizing</b>	<b>Example</b>
HIV patient, AIDS patient, AIDS orphan Positives or HIVers AIDS or HIV carrier	Person living with HIV. <b>Never</b> use HIV or AIDS as an adjective.	<i>Blanca is a person living with HIV and uses her story to advocate for continued funding of HIV-related services.</i>
Died of AIDS, to die of AIDS	Died of AIDS-related illness, AIDS-related complications or end-stage HIV	<i>Friedman died of AIDS-related illness on September 9.</i>
AIDS virus	HIV (AIDS is a diagnosis, not a virus. It cannot be transmitted)	<i>Typically, a person can live for many years with HIV before developing AIDS.</i>
Full-blown AIDS	There is no medical definition for this phrase. Simply use the term AIDS, or Stage 3 HIV.	<i>If a person's T-cell count drops below 200, they will be diagnosed with AIDS.</i>
HIV virus	This is redundant (HIV stands for human immunodeficiency virus); use HIV	<i>HIV is a type of virus called a retrovirus, and the drugs used to treat it are called antiretrovirals (ARV).</i>
Victim, Innocent Victim, Sufferer, Contaminated or infected	Person living with HIV (never use the term "infected" when referring to a person)	<i>As a person living with HIV, Linda wanted to share her story when the discussion about insurance coverage of pre-existing conditions hit the national stage.</i>
Dirty, Clean	HIV-positive, HIV-negative "Poz" is also sometimes used colloquially, but only when the person being referred to expresses that preference.	<i>Ricky is HIV-negative, so he takes PrEP to maintain that status.</i>
HIV-infected mother	Mother living with HIV	<i>Sam is a mother living with HIV and makes sure to take her medication daily.</i>

# STIGMATIZING v. NON-STIGMATIZING LANGUAGE

Mother to child transmission	Acquired HIV at birth. Perinatal transmission. “Vertical transmission” is also sometimes used.	<i>Perinatal transmissions have been nearly eliminated in Illinois.</i>
AIDS test	HIV screening, routine HIV screening.	<i>Our outreach van offers free HIV screenings Monday through Wednesday every week.</i>
To catch AIDS To contract AIDS To catch HIV	An AIDS diagnosis, developed AIDS, to contract HIV	<i>Gay men and men who have sex with men remain vulnerable to contracting HIV.</i>
Compliant	Adherent	<i>With the help of a text-reminder app on his phone, Jorge was able to stay adherent to his medication.</i>
Promiscuous	This is a value judgment and should be avoided. Sexual activities and behavior should be described in specifics, and only when that is helpful context for the overall story/situation.	<i>Bella has multiple sexual partners and wants to remain HIV-negative, so she chooses to take PrEP.</i>
Unprotected sex	Condomless sex, condomless sex with PrEP, Condomless sex without PrEP	<i>Jordan had condomless sex without PrEP a few weeks ago, so they’re getting an HIV screening at a nearby clinic.</i>
HIV infection (infections); Infected with HIV; “Disease”	HIV transmission (transmissions); Acquired HIV; Illness or condition	<i>New HIV transmissions in Illinois have decreased over the past decade.</i>
Consumer or consumers	The HIV community (or “audience” within marketing conversations)	<i>Illinois’ new U=U campaign is built by and celebrates the lives of the HIV community (“audience” would work here too) it intends to connect with.</i>

This chart was adapted from [HIVE’s HIV #LanguageMatters: Addressing Stigma by Using Preferred Language.](#)

## EMPOWERING IMAGES OF COMMUNITY MEMBERS

When sharing images of community members, images should be high resolution. Images of folks looking directly into the camera makes the person/people the focal point and can create a more powerful image.





## PEOPLE-FIRST & IDENTITY-FIRST LANGUAGE

Language is both personal and political. When referencing identities, GTZ-IL typically opts for people-first language, however, identities are ultimately determined by the person or community in reference. Whenever possible, ask the person or people being identified about their preference for people- or identity-first language and defer to their response.

### WHAT IS PEOPLE-FIRST LANGUAGE?

People-first language is language that puts the person before their diagnosis, disability or condition. This is important to keep in mind when referring to people who are living with HIV or people who use substances. This method of communication emphasizes that, first and foremost, everyone is a person and they are not defined by their diagnosis.

For more information regarding people-first language, please see the document below:

[Communicating With and About People with Disabilities](#)

### WHAT IS IDENTITY-FIRST LANGUAGE?

Identity-first language has emerged in reaction to the people-first language movement. It asserts that a person’s disability is an important part of their identity that should be embraced. Those who prefer identity-first language may treat their disability in the same way a person may relate to their gender, race or nationality.

For more information about identity-first language, see the resources below:

[What is Identity-First Language, & Should You Use It?](#)

[ASAN: Identity-First Language](#)

Person-first	Identity-first
“Person with a disability”	“Disabled person”

## COMMUNITIES & IDENTITIES

HIV can be transmitted to anyone, but certain communities are disproportionately impacted by the virus due to a variety of factors. GTZ-IL prioritizes these overrepresented communities and uses a mix of identity-first and people-first language depending on the historical linguistic evolution of each identity. When possible, **ask and defer to the preference of the person or people being identified.** Below are a few guidelines on how to describe groups and individuals who identify with a range of communities and identities related to GTZ-IL's work.

**African American** Hyphenate as an adjective only. Black (with a capital "B") is generally preferred.

*Example: The conference explored experiences shared by African Americans living with HIV. HIV-positive diagnoses among young Black gay males are on the rise.*

**Asylum Seeker** An asylum seeker is someone who is looking to leave the dangers of their home country in search of international protection. Asylum seekers must apply for protection in the country of destination and each case must be heard, according to US and international law. Not every asylum seeker will be recognized as a refugee. See **Refugee** listing. ([Rescue.org](https://www.rescue.org/))

**Cisgender** Term used to describe a person whose gender identity and/or gender expression is the same as what is typically associated with the sex they were assigned at birth.

**Gay and bisexual men** While not a perfectly inclusive term, it is preferred over "men who have sex with men (MSM)" in public-facing contexts. Avoid the term "homosexual."

**Heterosexual** A term used to describe people whose enduring physical, romantic and/or emotional attraction is to people of the opposite sex. Also straight. ([Gender Nation Glossary](#))

**Immigrant** An immigrant is someone who makes a conscious decision to leave their home and move to a foreign country with the intention of settling there. Someone who is an immigrant is not the same as a migrant. See **Migrant** listing. ([Rescue.org](https://www.rescue.org/))

**Migrant** A migrant is someone who is moving from place to place (whether that's within their home country or not), usually for economic reasons. Similar to immigrants, migrants are not forced to leave their homes due to persecution or violence, but rather to seek better opportunities. See **Refugee** and **Asylum Seeker** listings. ([Rescue.org](https://www.rescue.org/))

**Justice-involved community** Term to describe people who are or have been in jail or prison (which is also an acceptable description). Do not use "ex-offenders," "felons," "prisoners" or other similar terminology, unless preferred by the individual or group in reference. "Returning citizen" is acceptable in some cases, as is the academic "reentry population." Ultimately, each term is problematic and only describes one aspect of a person's life and experiences.



**Latino/Latina, Latinx** Preferred over “Hispanic.” Use Latino/Latina (with the forward slash) when referring to a mixed-gender group, or use the emerging, fully inclusive “Latinx,” which encompasses all genders.

**LGBTQ** Use instead of GLBT or LGBT. Avoid the term “homosexual.”

**Non-binary and/or Genderqueer** (Non-binary people/Genderqueer people)\*  
Terms used by some people who experience their gender identity and/or gender expression as falling outside the categories of man and woman. They may define their gender as falling somewhere in between man and woman, or they may define it as wholly different from these terms. The term is not a synonym for transgender or transsexual and should only be used if someone self-identifies as non-binary and/or genderqueer. Non-binary is sometimes shortened to enby. ([Gender Nation Glossary](#))

**People of color** Do not use “minorities.” “Communities of color” is an accepted variant. Or, better, be specific when referring to racial, ethnic and national groups.

**People with disabilities** Never use “the disabled” and only use “disabled people” if the group or person being referenced has expressed a preference for identity-first language.

**Queer** An adjective used by some people, particularly younger people, whose sexual orientation is not exclusively heterosexual (e.g. queer person, queer woman). Typically, for those who only identify as queer, the terms lesbian, gay, and bisexual are perceived to be too limiting and/or fraught with cultural connotations they feel don't apply to them. But many people identify as both queer and another sexual orientation (e.g. queer and a lesbian). Once considered a pejorative term, queer has been reclaimed by some LGBT people to describe themselves; however, it is not a universally accepted term, even within the LGBT community. When Q is seen at the end of LGBT, it typically means queer. ([Gender Nation Glossary](#))

**Men** Whenever GTZ-IL mentions ‘men,’ we are inclusive of transgender and cisgender men unless otherwise noted.

**Pronouns** Refer to individuals by their preferred gender pronouns in all cases. To be inclusive of all gender expressions, avoid using “he or she” or “him or her” when “they” or “their” would be appropriate as reference to an unknown/hypothetical person.

*Example: If someone arrives early, please ask them to wait in the lobby.*

**Refugee** Someone who has been forced to flee their home because of war, violence or persecution, often without warning. A person's refugee status is determined by an official entity, such as a government or the United Nations Refugee Agency, and they are unable to return home until conditions in their home lands are safe. However, refugees in the U.S. have the opportunity to become permanent residents and eventually citizens. See **Immigrant** listing. ([Rescue.org](#))

**Sex worker** Do not use “prostitute.”

**Transgender** Term used for people whose gender identity and/or gender expression differs from what is typically associated with the sex they were assigned at birth. Do not use “transgendered.” “Transgender” is an adjective, not a noun. Do not use “transgenders” or “a transgender”; rather, use “the transgender community” or “transgender individuals,” “person of trans experience,” “woman of trans experience,” “man of trans experience.” “Trans” or “trans\*” are generally accepted variants of “transgender.”

**Women** Whenever GTZ-IL mentions ‘women,’ we are inclusive of transgender and cisgender women unless otherwise noted.

## ADDITIONAL TERMS & CONCEPTS

**Affected** “People affected by HIV and AIDS” means those living with HIV and those most vulnerable to infection. People affected by HIV can be friends and family members.

*Example: “My children are affected by HIV but not living with it.”*

**Afflicted** Do not use. Alternatives: “living with HIV,” “person living with AIDS”

**At-risk** Avoid this term. “Vulnerable” is preferable to “at risk” or “at-risk.” See **Vulnerable** listing.

**Bloodborne** One word.

**Condom** When referring generally to this barrier device, use “internal and external condoms” to be inclusive of both styles. Internal and external condoms are often referred to as “female” and “male” condoms, respectively, but in an effort to de-gender these barrier devices, use “internal and external” on first reference and “male and female” condom for clarity.

**Disease** Do not use. Instead, use condition.

**Health care** Two words as a noun or adjective.

*Example: Health care reform has been a great success.*

**HIV/AIDS** Never “AIDS/HIV.” “The HIV epidemic” is preferred over “the AIDS epidemic,” since HIV is a virus and AIDS refers to a stage of HIV disease, and does not include everyone living with HIV. In general, use “HIV/AIDS” to describe institutions or issues related to the epidemic, but use “HIV and AIDS” or “HIV or AIDS” to describe the human experience of the disease.

*Example: The CDC reports that the lifetime cost to treat HIV for one person living with the virus is \$466,000. Thirty Chicagoans living with HIV and AIDS gathered at the capitol on Wednesday to advocate for protection of HIV/AIDS funding in the state.*

**Harm reduction** Harm reduction is a set of practical strategies and ideas aimed at reducing negative consequences associated with drug use. Harm Reduction is also a movement for social justice built on a belief in, and respect for, the rights of people who use drugs. ([Harm Reduction Coalition](#))

**PrEP** Pre-exposure prophylaxis (known as PrEP) is a daily prevention pill that is up to 99% effective when taken consistently and correctly.

**Preventive** Not “preventative.”

**Racism** Racism is different from racial prejudice, hatred, or discrimination. Racism involves one group having the power to carry out systematic discrimination through the institutional policies and practices of the society and by shaping the cultural beliefs and values that support those racist policies and practices. ([Dismantling Racism](#))

**Safer sex** Refers to anything we do to lower our risk — and our partners’ risk — of sexually transmitted infections. Some people call it “safe sex,” but this isn’t accurate — no type of sex with a partner can be guaranteed to be 100 percent safe. ([Planned Parenthood](#))

**Substance use** or drug use, not drug abuse. Use “People who use drugs” instead of “drug users.”

**Suicide** When referencing suicide, do not say “committed suicide” or refer to suicide as “successful,” “unsuccessful,” or a “failed attempt.” Instead describe as “death by suicide” or “killed themselves” and inform the audience without sensationalizing. Report on suicide as a public health issue and always offer hope and resources (e.g. The National suicide prevention Lifeline is 800-273-TALK (8255)) for the audience. Follow additional guidelines provided at [ReportingOnSuicide.org](#).

**TasP** Treatment as Prevention (TasP) means that people living with HIV on successful antiretroviral treatment — meaning their viral load is undetectable for at least six months — cannot transmit HIV sexually to their HIV-negative partners. See also **U=U**.

**Transition** Unless the individual prefers otherwise, do not use terms like “pre-operative,” “post- operative” or “sex change.”

**U=U (Undetectable equals untransmittable)** U=U is a public health campaign spearheaded by [Prevention Access Campaign](#). U=U promotes awareness around research that proves if a person living with HIV reaches an undetectable viral load through continued treatment, they will not transmit HIV. See also **TasP**.

**Vulnerable** When describing populations that experience increased prevalence of HIV diagnoses, avoid referring to their “risk” for HIV. Indicate that they are vulnerable to HIV instead, to better reflect socioeconomic and historical context for the prevalence.

*Example: Testing initiatives like MTI aim to provide access to HIV testing to communities that are vulnerable to HIV.*

**White fragility** Discomfort or defensiveness on the part of a white person when confronted by information about racial inequality and injustice. ([Oxford Dictionary](#))

**White privilege** An inherent preference for whiteness that saturates society. White privilege provides white people with benefits that are unearned — and that are not granted to people of color. All people are impacted by white privilege.

**White supremacy culture** This is the ideology that white people and their ideas, thoughts, beliefs and actions are superior to People of Color and their ideas, thoughts, beliefs and actions. White supremacy permeates throughout our culture in a number of implicit and explicit ways, especially in health care settings. ([Dismantling Racism](#))

## GETTING TO ZERO ILLINOIS MESSAGING & TALKING POINTS

### **What is Getting to Zero Illinois?**

Getting to Zero Illinois (abbreviated as GTZ-IL) is a statewide initiative to end the HIV epidemic in the state by 2030 in collaboration with community-based organizations, health care providers, government agencies, people living with HIV and other committed community members.

### **What do we mean by ‘zero’?**

The GTZ-IL initiative is focused on ending the HIV epidemic in Illinois by 2030 through reaching functional zero. This means that the number of new HIV diagnoses year after year are less than 100; at that point the epidemic can no longer sustain itself. Additionally, we want to see zero people living with HIV who are not connected to treatment and supportive services as well as zero people vulnerable to HIV who do not have access to PrEP and other prevention options – including information about those prevention options.

### **Why do we need a plan?**

We need a plan to coordinate our efforts to end the HIV epidemic throughout the state. GTZ-IL gives us all in the HIV workforce the same goals to work toward and allows other sectors to get on board and align themselves where they see fit. GTZ-IL helps us to strive for a unified vision so that we can get there!

### **What do we mean by ‘viral suppression’?**

When a person living with HIV engages in antiretroviral therapy (ART) treatment for an extended period of time, their viral load (the amount of HIV in the blood) may be so low that it is not detected by a viral load test. Viral suppression does not mean a person is cured; HIV still remains in the body, just at such a low level that it cannot be transmitted. ([AIDSinfo](#))

### **What do we mean by ‘undetectable’?**

Related to ‘viral suppression,’ ‘undetectable’ describes the viral load in the blood of a person living with HIV who engages in antiretroviral therapy (ART) treatment for an extended period of time and their viral load remains undetectable for at least six months. ([AIDSinfo](#))

### **What does it mean to be ‘on PrEP’?**

PrEP is a pill and program that is often referred to as ‘seasonal’ because being ‘on PrEP’ has no defined time. You are ‘on PrEP’ if you are taking your prescription every day and attending your clinic appointments, getting tested for HIV and other STDs every three months. You are ‘off PrEP’ if you are not taking the prescription every day. People can cycle on and off as much as they want – as long as it is done with their provider.

### **What do we mean by ‘social determinants of health’?**

The social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. ([World Health Organization](#))

## **How can organizations get involved?**

Organizations can get involved with GTZ-IL by visiting our [partners page](#) at GTZIllinois.hiv to find out more information. They can also email the project manager, Sara Semelka (ssemelka@aidschicago.org) for additional information.

## **How can individuals can get involved?**

Individuals can find out ways to get involved by visiting our website and clicking our 'Get Involved' tab to join our email list, sign up to volunteer with one of our work groups or contact us directly at [info@gtzillinois.hiv](mailto:info@gtzillinois.hiv). Individuals can also email Sara Semelka (ssemelka@aidschicago.org) to join our Basecamp group and receive regular updates.

**Go to our website ([GTZIllinois.hiv](http://GTZIllinois.hiv)) to learn more about Getting to Zero Illinois!**



**CITED SOURCES:**

“Communicating With and About People Living with Disabilities”. *Centers for Disease Control and Prevention*.  
[https://www.cdc.gov/ncbddd/disabilityandhealth/pdf/disabilityposter\\_photos.pdf](https://www.cdc.gov/ncbddd/disabilityandhealth/pdf/disabilityposter_photos.pdf).

“Definition of white fragility in English”. *Oxford University Press*.  
[https://en.oxforddictionaries.com/definition/white\\_fragility](https://en.oxforddictionaries.com/definition/white_fragility).

“Gender Nation Glossary”. *Refinery29*. <https://www.refinery29.com/lgbtq-definitions-gender-sexuality-terms>.

“HIV/AIDS Glossary: Viral Suppression”. *AIDSinfo*.  
<https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/1650/viral-suppression>.

“HIV/AIDS Glossary: Undetectable Viral Load”. *AIDSinfo*.  
<https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/876/undetectable-viral-load>.

“Identity-First Language”. *Autistic Self Advocacy Network*.  
<http://autisticadvocacy.org/about-asan/identity-first-language/>.

Lynn, Vickie, et al. “HIV #LanguageMatters: Addressing Stigma by Using Preferred Language”. *HIVE*. <https://www.hiveonline.org/wp-content/uploads/2016/01/Anti-StigmaSign-Onletter-1.pdf>.

“Migrants, Asylum Seekers, Refugees and Immigrants: What's the Difference?” *International Rescue Committee (IRC)*, 11 Dec. 2018,  
[www.rescue.org/article/migrants-asylum-seekers-refugees-and-immigrants-whats-difference](http://www.rescue.org/article/migrants-asylum-seekers-refugees-and-immigrants-whats-difference).

“Principles of Harm Reduction”. *Harm Reduction Coalition*.  
<https://harmreduction.org/about-us/principles-of-harm-reduction/>.

“Racism Defined.” *Dismantling Racism*. <http://www.dismantlingracism.org/racism-defined.html>.

Thorpe, JR. “What is Identity-First Language, & Should You Use It?”. *Bustle*, 9 Aug 2017, [www.bustle.com/p/what-is-identity-first-language-should-you-use-it-74901](http://www.bustle.com/p/what-is-identity-first-language-should-you-use-it-74901).

U=U campaign. *Prevention Access*. <https://www.preventionaccess.org/>.

“What’s the difference between ‘safe sex’ and ‘safer sex’?”. *Planned Parenthood*.  
<https://www.plannedparenthood.org/learn/teens/ask-experts/what-is-the-difference-between-safe-sex-and-safer-sex>.

“White Supremacy Culture”. *Dismantling Racism*.  
<http://www.dismantlingracism.org/white-supremacy-culture.html>.

**ADDITIONAL RESOURCES:**

[Making Media Work for HIV Justice](#) - Media’s guide to talking about HIV and the HIV community.

[AP stylebook](#) - Unless otherwise stated in this guide, Getting to Zero Illinois follows the AP stylebook.