

“Words Matter HIV Toolkit” Aims to Destigmatize the Topic Among Black Youth

The National Black Justice Coalition HIV tool kit offers advice on using people-first language, initiating difficult conversations and more.

April 13, 2023 By Laura Schmidt

In honor of National Youth HIV & AIDS Awareness Day (NYHAAD) April 10, the National Black Justice Coalition (NBJC) released a new [Words Matter HIV Toolkit](#) with resources to support Black youth, who are disproportionately impacted by HIV.

The Words Matter HIV Toolkit aims to educate and encourage people to have stigma-free conversations surrounding the virus. It also urges individuals who are living with HIV to take antiretrovirals and try to maintain an undetectable level. For folks who are HIV negative but at risk, the tool kit recommends pre-exposure prophylaxis (PrEP), the daily pill and long-acting injections that are highly effective at preventing HIV.

As NBJC states, these issues are particularly relevant to Black Americans. “In 2018, young Black gay, bisexual, and same-gender-loving men made up 51% of new HIV diagnoses among young gay and bisexual men overall,” [reads an NBJC statement](#) regarding the youth awareness day. “The rate of new infections among Black girls and women aged 13 to 24 is six times higher than that of young Hispanic women and 20 times that of young white women.”

A related [NBJC fact sheet](#) spells out key facts:

- 46% of Black young people say HIV is a serious concern for people they know.
- 18% of people with HIV aged 18 to 24 had sex without using any HIV prevention strategy in the past 12 months.
- 16% of people aged 16 to 24 who could benefit from PrEP were prescribed PrEP in 2019.
- New HIV diagnoses in the U.S. fell by 16% for people between the ages of 13 to 24 from 2015 to 2019.

- In 2019, 3,209 Black gay, bisexual, and same-gender-loving boys and men aged 13 to 24 were diagnosed with HIV, compared to 948 white boys and men of the same age group.
- In 2016, more than half of gay, bisexual, and same-gender-loving young people with HIV were Black.

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

The tool kit aims to increase the number of Black people getting tested for HIV, reduce the number of Black people acquiring the virus, increase support for Black people living with HIV, provide education and much more.

Words Matter breaks issues down into sections such as “Learning & Unlearning: What Is HIV Stigma?” This section provides examples of stigmatized language to avoid, such as “AIDS test,” which is an inaccurate term because AIDS does not refer to the virus and the antibodies the tests look for, rather AIDS is a condition that develops from HIV. The preferred term is “HIV test.”

The NBJC tool kit also suggests starting community conversations about HIV and AIDS and provides helpful instructions for doing so. It also offers thought-provoking questions to be contemplated alone or with others.

“Language can be used to create spaces where people feel safe, comfortable, and supported including through personal and difficult conversations,” the [tool kit reads](#). “Language is a powerful tool in disrupting bias and stigma as well as facilitating healing.”

For more from the NBJC, [click here](#) to read and download the full Words Matter HIV Toolkit.

And to learn more about the virus, including testing, treatment and prevention, see [the POZ Basics on HIV and AIDS](#). For example, it clarifies the difference between HIV and AIDS:

What is HIV?

HIV stands for human immunodeficiency virus. HIV is a virus, like the flu or cold. A virus is nothing than a set of instructions for making new viruses, wrapped up in some fat, protein and sugar. Without living cells, a virus can’t do anything—it’s like a brain with no body. In order to make more viruses (and to do all of the other nasty things that viruses do), a virus has to infect a cell. HIV mostly infects CD4 cells, also known as T cells, or T-helper cells. These are white blood cells that coordinate the immune system to fight disease. Once inside the cell, HIV starts producing millions of little viruses, which eventually kill the cell and then go out to infect other cells. All of the drugs marketed to treat HIV work by interfering with this process.

What is AIDS?

AIDS (acquired immune deficiency syndrome) is a condition caused by HIV. This virus attacks the immune system, the body's "security force" that fights off infections. When the immune system breaks down, you lose this protection and can develop many serious, often deadly infections and cancers. These are called "opportunistic infections (OIs)" because they take advantage of the body's weakened defenses. You have heard it said that someone "died of AIDS." This is not entirely accurate, since it is the opportunistic infections that cause death. AIDS is the condition that lets the OIs take hold.