

## HIV and Transgender Communities

### Strengthening Prevention and Care

Nearly 1 million people in the United States identify as transgender.<sup>1</sup> The term transgender describes a person whose gender identity or expression is different from their sex assigned at birth and is often used as an umbrella term to include people of additional, non-cisgender identities. Transgender people, particularly transgender women, are heavily affected by HIV and transgender women are among the groups most disproportionately affected by HIV in the U.S.

To end the HIV epidemic, CDC is actively working with public health partners, other federal agencies, and community leaders to improve HIV prevention and care for transgender people nationwide and reduce health disparities.

### What the Available Data Tell Us

#### HIV Prevalence

To estimate the percentage of transgender people with HIV in the U.S., or HIV prevalence, CDC scientists conducted a meta-analysis of 88 studies published from 2006-2017. The analysis confirmed that transgender people are disproportionately affected by HIV. Laboratory-confirmed HIV prevalence was 14.1% for transgender women, 3.2% for transgender men, and 9.2% for transgender people overall.<sup>2</sup> By comparison, estimated HIV prevalence for U.S. adults overall is less than 0.5%.<sup>3, 4</sup>

Another recent CDC study highlighted the severe toll of HIV among transgender women. Surveys conducted in seven U.S. cities found that four in ten transgender women had HIV, with stark racial and ethnic differences in HIV rates among respondents. 62% of Black transgender women and 35% of Hispanic/Latina transgender women surveyed had HIV, compared to 17% of White transgender women. Nearly two-thirds of the women surveyed lived at or below the poverty level, and 42% had experienced homelessness in the past 12 months.<sup>5</sup>

### Improving Data on HIV Among Transgender Populations

Accurate, timely data are critical for designing, directing, and evaluating HIV prevention programs. But since the beginning of the epidemic, there has been limited national information on the impact of HIV among transgender populations. In large part, this is because there has been no reliable system for collecting and sharing both sex and gender identity information in health records.

In 2020, CDC released National HIV Surveillance System data for transgender people for three *Ending the HIV Epidemic in the U.S.* (EHE) core indicators: diagnoses of HIV infection, linkage to HIV medical care, and viral suppression. This data release was the result of many years of effort by CDC and state and local health departments to standardize and improve data collection, quality, and reporting. These efforts included:

- Revising the data fields used in CDC's National HIV Surveillance System (NHSS) to better account for sex and gender identity.
- Issuing recommendations and statistical tools for health departments to collect information on current gender identity and report these data to the NHSS.
- Informing healthcare providers about the importance of collecting complete data on sex and gender identity.
- CDC continues to improve information gaps on HIV among transgender people by:
  - Analyzing data on HIV testing among transgender people through CDC's Behavioral Risk Factor Surveillance System.
  - Funding health departments to study behaviors that increase HIV transmission risk, testing behaviors, and the use of prevention services among transgender women through CDC's National HIV Behavioral Surveillance system.



## HIV Diagnoses



Since 2018, CDC has published national-level HIV diagnosis data by gender, which includes data for transgender people and people of additional gender identities. The most recent surveillance report found that HIV diagnoses among transgender adults and adolescents increased 9% in the U.S. and six dependent areas from 2015 to 2019.

In 2019, transgender people accounted for approximately 2% of HIV diagnoses among all adults and adolescents. The vast majority (93%) of HIV diagnoses among transgender people occurred among transgender women. Surveillance data from 2019 also show:

- 46% transgender women and 41% of transgender men who received an HIV diagnosis were African American
- 77% of transgender women and 91% of transgender men received an HIV diagnosis between the ages of 13 and 34
- 43% of transgender women and 41% of transgender men who received an HIV diagnosis lived in the Southern U.S.<sup>6</sup>

## Systemic Factors that Contribute to the HIV Epidemic Among Transgender People

- **Many transgender people face stigma, discrimination, social rejection, and exclusion** that can prevent them from accessing health care, education, employment, and housing and can contribute to poor mental health outcomes. Transgender people also experience high rates of incarceration and violence. A recent CDC survey of high school students who identify as transgender found that in the year prior to the survey, 35% had been bullied at school and 35% had attempted suicide. These factors affect the health and wellbeing of transgender people, increasing the likelihood they may acquire HIV.<sup>7, 8, 9, 10, 11</sup>

| KEY TERM                 | DEFINITION  |
|--------------------------|---|
| <b>Gender Expression</b> | A person's outward presentation of their gender (for example, how they act, dress, speak, and behave). Gender expression does not necessarily correspond to listed sex at birth or gender identity. |
| <b>Gender Identity</b>   | A person's internal understanding of their own gender (for example, being a man/male, woman/female, both, neither, or another gender).  |
| <b>Transgender</b>       | Describes a person whose gender identity or expression is different from their sex assigned at birth. Transgender is also used as an umbrella term to include additional non cisgender identities.  |
| <b>Cisgender</b>         | Describes a person whose gender identity or expression is the same as their sex assigned at birth (i.e., a person who is not transgender).  |
| <b>Transphobia</b>       | Describes fear of, or discrimination against, transgender or gender-nonconforming people, or people who are perceived to be transgender.  |

- **Transgender people of color also face systemic racism**, which can lead to HIV disparities. One study found that young racial/ethnic minority transgender women were significantly more likely to experience discrimination than young White transgender women.<sup>12</sup> Other surveys have found that transgender people of color report higher rates of poverty, homelessness, and unemployment compared to White transgender people.<sup>13, 14</sup> These factors can result in increased HIV transmission risk.
- **Insensitivity to transgender-specific health needs** by providers, including disregard for a transgender person's gender identity, can be a significant barrier for transgender people with HIV seeking quality treatment and care services.<sup>15</sup> One study found that transgender youth were more likely to miss HIV care appointments if they were treated negatively because of their gender identity.<sup>16</sup> Another study found that unmet needs for gender affirmation, including surgical needs and not being on hormones, were significantly associated with HIV treatment interruptions.<sup>17</sup>
- **The effectiveness of HIV behavioral interventions, developed for other groups most affected by HIV and adapted for use with transgender people, is understudied.** According to a 2017 study, most existing interventions target behavior change among transgender women, with only one HIV prevention program evaluated for transgender men. Evidence-based multilevel interventions that address the structural, biomedical, and behavioral factors that increase HIV transmission risk among transgender populations, including transgender men, are needed to address disparities in HIV prevalence.<sup>18</sup>
- **Transgender people are not being sufficiently reached by pre-exposure prophylaxis (PrEP).**<sup>19</sup> Studies have found that low uptake of PrEP among transgender women may be due to a range of factors, including medical mistrust due to experiences of transphobia, lack of trans-inclusive marketing, and concerns about drug interactions between hormones and PrEP.<sup>20, 21</sup>

## CDC's Support for Transgender-Specific HIV Prevention

CDC is collaborating with many partners to intensify HIV prevention efforts for transgender people and build the base of evidence needed to improve programs and track progress.

### Delivering High-Impact Prevention



Transgender people are a priority for CDC's core HIV prevention funding programs, including funding to state and local health departments and community-based organizations (CBOs). CDC is providing 36 CBOs with focused funding of nearly \$14 million per year over five years to support HIV testing, linkage to care, and prevention services for transgender youth of color and young gay and bisexual men of color. CDC also funds a national network of capacity-building providers that help health departments and CBOs provide culturally relevant programs, services, and interventions for transgender people.

A new pilot program will fund CBOs to develop community-to-clinic health models to provide access to integrated status-neutral HIV prevention and care services, gender-affirming services that include access to OR referral to hormone therapy, and primary health care. The funding opportunity also supports linking transgender persons to services as needed for mental health and substance use disorder and other essential support services. These three elements working together will provide a supportive foundation that will lead to an increase by transgender persons to access HIV prevention and treatment services, decrease HIV transmission, and improve their overall health and wellbeing.

Through the [Ending the HIV Epidemic in the U.S.](#) initiative, CDC supports efforts to advance health equity and overcome barriers to HIV prevention and treatment in the 57 areas of the country hardest hit by HIV. The initiative requires funded recipients to actively engage people with and affected by HIV in the design and implementation of localized HIV prevention activities. This effort includes the use

or expansion of innovative community-tailored HIV testing and care strategies for transgender people.

CDC's *Together-TakeMeHome* self-testing pilot program is an internet-based program that successfully provided 100,000 free HIV test kits to anyone who requested one, with a focus on reaching Black and Latina transgender women, among other groups. Among transgender persons who ordered test kits, 24% of transgender women and 30% of transgender men reported never being tested for HIV.

Finally, as part of its [Transforming Health](#) resource, CDC offers educational materials for healthcare and social service providers to help them improve care for transgender people with HIV and make clinical environments more welcoming to transgender patients.

## Advancing HIV Prevention Research



While many prevention programs have been adapted for use with transgender populations, to date, few have been tested and proven effective. To address this gap, CDC is working with partners to develop new prevention programs, adapt existing ones, and rigorously assess their impact on HIV transmission. For example:

- As part of its [Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention](#), CDC included the “Couples with HIV Intervention Program,” which focuses on reducing behaviors that increase HIV transmission risk among transgender women and their primary cisgender male partners. The Compendium also includes “Link LA,” a peer-navigator intervention to improve linkage to and retention in HIV care among transgender women with HIV who are released from jail.
- CDC is supporting CBOs in Atlanta and Chicago to pilot [Transgender Women Involved in Strategies for Transformation \(TWIST\)](#), a peer-led educational intervention that seeks to reduce behaviors that increase HIV transmission risk and sexually transmitted diseases among transgender

women with HIV. TWIST was developed in collaboration with transgender women and was adapted from an existing HIV intervention focused on cisgender women.

- CDC is studying two locally developed or adapted interventions that are designed to deliver a combination of HIV prevention and other support services to transgender people who have sex with men and other people who could benefit from prevention services. These interventions are a combination of mutually reinforcing biomedical, behavioral, and social/structural intervention components that together have the potential to reduce participants' likelihood of acquiring HIV.

## Raising Awareness, Engaging Communities



Evidence-based health marketing campaigns can help motivate people to know their level of risk, take actions to protect their health, and seek care and treatment. CDC's [Let's Stop HIV Together](#) campaign provides and disseminates an extensive portfolio of campaign resources, including tailored resources for transgender audiences. *Let's Stop HIV Together* aims to empower communities, partners, and healthcare providers to promote testing, prevention, and treatment, as well as reduce HIV stigma. The campaign's [HIV Nexus](#) clinician portal includes the Transforming Health website featuring information and materials for health care providers, with the goal of reducing new HIV infections and improving the health of transgender people. The campaign is part of the national [Ending the HIV Epidemic in the U.S.](#) initiative.

*Let's Stop HIV Together* engages groups most burdened by HIV and has strong partnerships, including with organizations, individual ambassadors, and influencers representing transgender communities. CDC also supports [National Transgender HIV Testing Day](#) each June by engaging in partnership activities and disseminating materials and messages for transgender audiences and for clinicians serving transgender patients.

## Need for Collective Action

Despite significant challenges, there is much that can be done now to address key gaps in HIV prevention and care for transgender people. CDC plays a critical role, and action is also needed from many other partners:

- **Federal health agencies** can promote gender-affirming and status-neutral approaches to HIV prevention and care that consider the needs of the whole-person ahead of their HIV status – and provide guidance to state and local health departments with best practices for implementation. They can collect data on gender identity and include transgender people and people of other gender identities in federal decision-making and advisory committees. Agencies can also develop funding opportunities focused on reducing stigma and improving HIV prevention and care programs for transgender people.
- **State and local health departments** can continue to improve data on HIV among transgender people by collecting, compiling, and reporting data on sex and gender identity and training providers and organizations on how to collect and report such data. They can also fund local programs focused on eliminating stigma and improving access to HIV prevention and care for transgender people.

- **Healthcare providers and community-based organizations** can use a status-neutral framework to provide culturally informed, comprehensive HIV care for transgender people. This framework includes educating patients about effective prevention methods like PrEP; creating linkages to appropriate support services so transgender people with HIV can stay engaged in care and become virally suppressed; and providing tailored care that also addresses other transgender-specific health needs.
- **Elected and community leaders** can advocate for policies that support the health and wellbeing of transgender people and work with their communities to reduce HIV-related stigma.
- **Researchers and their institutions** can conduct additional research to expand the body of evidence on effective strategies to reduce HIV infections and improve HIV and other health outcomes for transgender people.

There is great potential to address the HIV prevention and health care needs of transgender people. CDC will continue working with partners and the community to ensure that transgender people can access the HIV prevention and care services they need to live long, healthy lives.



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