

Literature Review on HIV-Related Disparities to Implement a National Quality Improvement Initiative: end+disparities ECHO Collaborative

*“Of all the forms of inequality, injustice in health care is the most shocking and inhumane”
- Martin Luther King*

A) Introduction and Background

Since the emergence of HIV/AIDS in the early 1980s, the global community has witnessed momentous innovations that have significantly changed the landscape of HIV care.¹ In particular, advancements in antiretroviral therapy (ART) over the last twenty years have transformed HIV/AIDS from a rapidly progressing ailment to what most consider a chronic disease.² ART causes a significant reduction in viral load in the body, with the ultimate goal of reaching undetectable levels, or “viral suppression.”³ ART and viral suppression also play critical roles in the prevention of HIV transmissions.

Based on three recent studies, the HIV/AIDS Director of Prevention at the Center for Disease Control (CDC) released a statement in September, 2017 declaring “people who take ART daily as prescribed and achieve and maintain an undetectable viral load have effectively no risk of sexually transmitting the virus to an HIV-negative partner.”⁴ Despite the clinical success of ART in causing viral suppression, reductions in HIV-related morbidity and mortality are uneven across subpopulations of people living with HIV (PLWH) due to unequal access to care and variations in the quality of care provided.⁵

Approximately 70% of the estimated 1.2 million PLWH in the United States are not virally suppressed.⁶ A breakdown of the subpopulations contributing to the virally non-suppressed population paint a striking picture of disparities in HIV care since specific populations bear a disproportionate burden of HIV. At 16%, the rate of viral suppression among black men who have sex with men (MSM) is less than half the rate of viral suppression among white MSM (34%).⁷ In 2014, the rate of HIV diagnoses among black women was 18 times higher than that of white women.⁸ A study in 2013 showed that while the average suppression rate for all PLWH is

¹ U.S. Department of Health & Human Services. HIV.gov: Overview—a timeline of HIV/AIDS. Updated 2016. Available from <https://www.hiv.gov/hiv-basics/overview/history/hiv-and-aids-timeline>

² Olalla G, Knobel H, Carmona A, Guelar A, López-Colomés JL, and Caylà JA. Impact of adherence and highly active antiretroviral therapy on survival in HIV-infected patients. *J Acquir Immune Defic Syndr*. 2002;30(1):105-110.

³ Saag, M.S. & Holodniy, Mark & Kuritzkes, D.R. & O'Brien, W.A. & Coombs, R & Poscher, M.E. & Jacobsen, Donna & Shaw, G.M. & Richman, D.D. & Volberding, P.A. (1996). HIV viral load markers in clinical practice. *Nature medicine*. 2. 625-9. 10.1038/nm0696-625.

⁴ <https://www.cdc.gov/hiv/library/dcl/dcl/092717.html>

⁵ Wong MD, Cunningham WE, Shapiro MF, Andersen RM, Clearly PD, Duan N, et al.; HCSUS Consortium. Disparities in HIV treatment and physician attitudes about delaying protease inhibitors for nonadherent patients. *J Gen Intern Medicine*. 2004;19(4):366–374.

⁶ Bradley H, Hall HI, Wolitski RJ, Van Handel MM, Stone AE, LaFlam M, et al. Vital signs: HIV diagnosis, care, and treatment among persons living with HIV — United States, 2011. *MMWR*. 2014;63(47):1113-1117

⁷ Rosenberg ES, Millett GA, Sullivan PS, del Rio C, and Curran JW. Understanding the HIV disparities between Black and White men who have sex with men in the USA using the HIV Care Continuum: a modelling study. *Lancet HIV*. 2014;1(3):e112-e118.

⁸ Ivy, W., Nwangwu-Ike, N., & Paz-Bailey, G. (2017). Reductions in HIV Diagnoses Among African American Women. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 75. doi:10.1097/qai.0000000000001400

approximately 25%, approximately 15% of youth are virally suppressed.⁹ Transgender women—those assigned male gender at birth, but identify as female—have a significantly lower ART dose adherence rate and durable viral suppression compared to cisgender men, despite having similar rates of receiving care, treatment, and supportive services.¹⁰

The CDC defines disparities as “differences in health outcomes or health determinants observed between populations.”¹¹ It is commonly understood within the public health field that a group is a health disparity population when “there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population.”¹² Addressing these disparities is important in aligning HIV care with national public health priorities. To reduce disparities requires focusing on disproportionately affected communities and populations. Preliminary interviews to prepare for the end+disparities Learning Exchange identified four subpopulations to focus public health improvement efforts on. Although the disparities faced by these four groups are certainly not the only disparities that exist within HIV care, the interviews highlighted the importance of focusing on MSM of Color, African American and Latina Women, Youth (age 13-24), and Transgender People.¹³

In alignment with national public health priorities, HRSA’s Ryan White HIV/AIDS Program Center for Quality Improvement and Innovation (CQII) (Center) in close collaboration with the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) proposes to address HIV-related disparities as the key focus of its next national quality improvement initiative. Building upon the impact of its in+care Campaign,¹⁴ HIV Cross-Part Care Continuum Collaborative (H4C),¹⁵ and end+disparities Learning Exchange,¹⁶ the Center works toward reducing HIV-related disparities in key communities to ensure that all PLWH are virally suppressed and have optimal health outcomes.

This new 18-month national quality improvement initiative, called the end+disparities ECHO Collaborative, focuses on reducing disparities by increasing viral suppression rates in four subpopulations of people living with HIV: MSM of Color, African American and Latina Women, Youth (aged 13 to 24 years), and Transgender People. The Collaborative engages Ryan White HIV/AIDS Program (RWHAP)-funded recipients and sub-recipients nationwide across all Parts. Regionally-based improvement groups are engaged in this Collaborative to help HIV providers improve their underlying systems of HIV care, build quality improvement capacity, routinely

⁹ Hall HI, Frazier EL, Rhodes P, Holtgrave DR, Tang T, Gary KM, et al. Differences in human immunodeficiency virus care and treatment among subpopulations in the United States. *JAMA Intern Med.* 2013;173(14):1337-44.

¹⁰ Mizuno Y, Frazier EL, Huang P, and Skarbinski J. Characteristics of transgender women living with HIV receiving medical care in the United States. *LGBT Health.* 2015;2(3):228-234.

¹¹ Johnson AS, Beer L, Sionean C, Hu X, Furlow-Parmley C, Le B, et al. CDC health disparities and inequalities report: HIV infection—United States, 2008 and 2010. *MMWR.* 2013;62(3):112-119.

¹² Office of National AIDS Policy. National HIV/AIDS strategy: updated to 2020. July 2015. Available from <https://www.whitehouse.gov/administration/eop/onap/>

¹³ NQC Concept Paper—Developing a Quality Improvement Initiative to End Disparities in HIV Care

¹⁴ JSI Research & Training Institute and National Quality Center. National Quality Center Impact Evaluation Report; Making a Mark: Demonstrating Health Impacts among Ryan White HIV/AIDS Program Grantees Utilizing the National Quality Center – in+care Campaign. 2014 June. Available from <https://nationalqualitycenter.glasscubes.com/share/s/1181lbgjlsunqfdftscmvd7o8?2>

¹⁵ JSI Research & Training Institute and National Quality Center. National Quality Center Impact Evaluation Report; Making a Mark: Demonstrating Health Impacts among Ryan White HIV/AIDS Program Grantees Utilizing the National Quality Center – HIV Cross-Part Care Continuum Collaborative. 2016 September. Available from <http://nationalqualitycenter.org/nqc-activities/collaboratives/h4c-collaborative/>

¹⁶ NQC Concept Paper—Developing a Quality Improvement Initiative to End Disparities in HIV Care

monitor performance measures, and create a sustainable infrastructure that will last beyond the formal conclusion of the Collaborative. The innovative Project Extension for Community Health Outcomes (ECHO) framework, which uses video conferencing technologies to build specialized knowledge and capacity for primary care providers in rural regions of the country, is adapted for the needs of this Collaborative. The virtual communication platform of this model enables participants to attend a higher number of meetings and eliminates potential barriers that meeting physically may pose for some recipients and sub-recipients. Additionally, special interest groups (affinity groups) that focus on different subpopulations of interest across the nation hold routine virtual meetings (affinity sessions) to help participants gain subpopulation-specific knowledge, promote peer sharing and exchange, and provide feedback on quality improvement implementation processes from both a peer and expert perspective.

This Literature Review provides an overview and rationale for this important public health goal by describing the individual and population-based benefits congruent with reducing HIV-related disparities.

B) HIV Disparities

The national viral suppression rate of 30% indicates that significantly more needs to be done to improve health outcomes for all PLWH. The statistics of those who are virally non-suppressed highlight disparities in HIV care (see Figure 1). However, an understanding of the disproportionate burden of HIV felt by vulnerable subpopulations can provide the impetus for systemic and sustainable improvements. Smaller subpopulations with a disproportionately high prevalence of HIV are therefore the most actionable groups for targeted public health interventions that simultaneously reduce overall levels of morbidity, mortality, and onward HIV transmission.

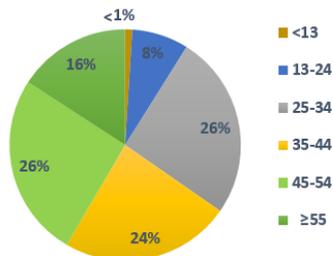
Data from the 2016 CDC HIV Surveillance Report show discrepancies in the number of diagnoses of HIV infection based on age, race/ethnicity, region, and transmission category.¹⁷ The gap in care for specific subpopulations is well documented.

Figure 1: Diagnoses of HIV Infection by Selected Demographics¹⁸

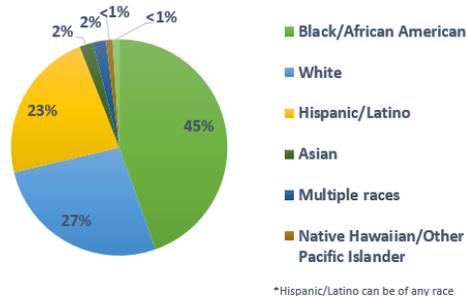
¹⁷ CDC. HIV/AIDS Surveillance Report: Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data—United States and 6 Dependent Areas, 2015. Vol. 27 Published 2016 Nov. Available from <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2015-vol-27.pdf>

¹⁸ Graphic created using data from CDC. HIV/AIDS Surveillance Report: Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data—United States and 6 Dependent Areas, 2015. Vol. 27 Published 2016 Nov. Available from <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2015-vol-27.pdf>

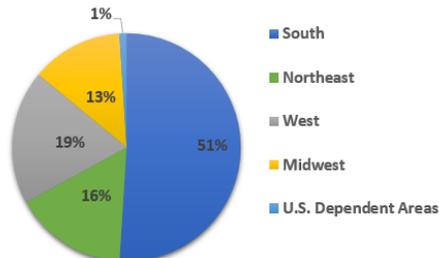
DIAGNOSES OF HIV INFECTION BY AGE AT DIAGNOSES - 2015



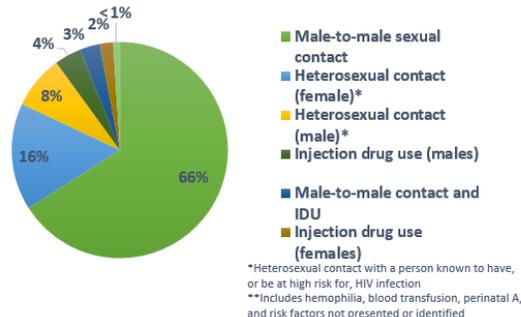
DIAGNOSES OF HIV INFECTION BY RACE/ETHNICITY - 2015



DIAGNOSES OF HIV INFECTION BY REGION - 2015



DIAGNOSES OF HIV INFECTION BY TRANSMISSION CATEGORY - 2015



The end+disparities ECHO Collaborative aims to empower HIV providers across the United States to implement local improvement efforts, impacting the care provided to underserved subpopulations by reducing HIV-related disparities and providing equitable care for PLWH. The Center’s new initiative actively promotes the implementation of interventions to increase the viral suppression rates for the following four subpopulations:

- MSM of Color
- African American and Latina Women
- Youth (aged 13 to 24 years)
- Transgender People

1) MSM of Color

Gay, bisexual, and other men who have sex with men (MSM) of all races and ethnicities are disproportionately affected by HIV in the United States.¹⁹ MSM represent approximately 2% of the U.S. population, yet they accounted for 70% of all new HIV infections in 2014. In 2014, there were an estimated 511,290 MSM living with diagnosed HIV infections; of those, 156,389 were black, 210,659 were white, and 110,158 were Latino.²⁰ In a previous publication, the estimated rate of HIV infection among MSM was approximately 46 times that of all other men.²¹

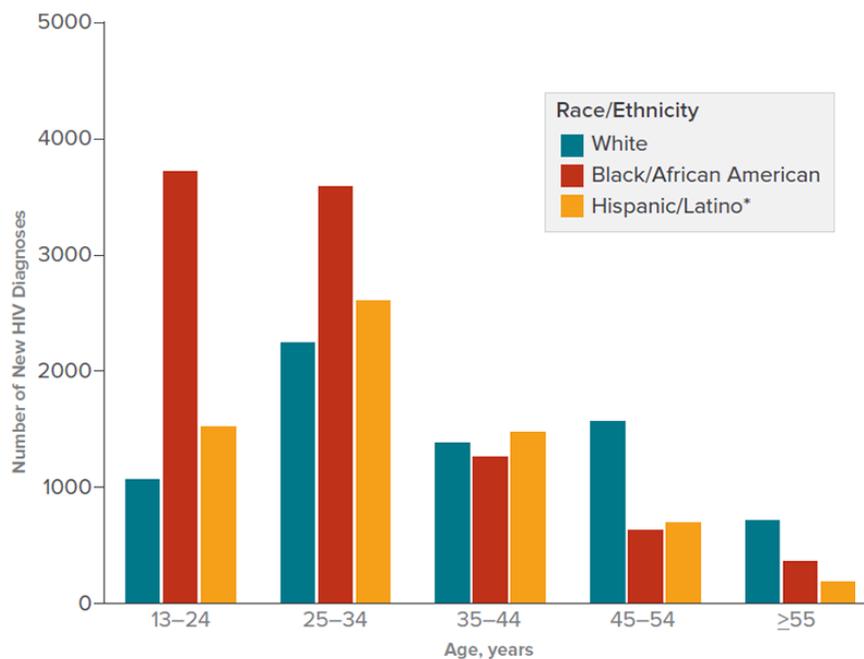
¹⁹ CDC. HIV/AIDS: HIV among gay and bisexual men. Updated 2017 Sep 27. Available from <http://www.cdc.gov/hiv/group/msm/>

²⁰ CDC. Diagnoses HIV infection among adults and adolescents in metropolitan statistical areas—United States and Puerto Rico, 2015. HIV Surveillance Supplemental Report 2017;22(1):1-88. Accessed 2017 Nov 7.

²¹ Johnson AS, Beer L, Sionean C, Hu X, Furlow-Parmley C, Le B, et al. CDC health disparities and inequalities report: HIV infection—United States, 2008 and 2010. *MMWR*. 2013;62(3):112-119.

Even within the overburdened subpopulation of MSM, MSM of color are particularly underserved. CDC data indicate that although black people make up 12% of the U.S. population, they accounted for 45% of PLWH in 2015.²² A majority (78%) of black men with HIV contracted the disease by male to male contact.²³ Among MSM, black MSM is the group most affected by HIV (see Figure 2).²⁴ In 2015, black MSM accounted for more new HIV infections as white MSM, despite the overall black population being significantly smaller.²⁵ There were an estimated 10,315 new HIV infections among black MSM, in comparison to an estimated 7,570 new HIV infections among white MSM, and 7,013 new HIV infections among Latino MSM.

Figure 2: Estimated New Diagnoses of HIV among MSM, by Race/Ethnicity and Age at Infection, 2015 in the United States²⁶



Some research has suggested that black MSM are more at risk for HIV even when they have the same or fewer risk behaviors as MSM of other races. The likelihood of having unprotected anal intercourse, engaging in commercial sex work, or having sex with a known HIV-infected partner was not higher among black MSM than white MSM.²⁷

²² CDC. HIV/AIDS: HIV among African Americans. Updated 2017 Oct 26. Available from <http://www.cdc.gov/hiv/group/raciaethnic/africanamericans/>

²³ CDC. Health disparities in HIV/AIDS, viral hepatitis, STDs, and TB: African Americans/Blacks. Updated 2014 March 20. Available from <http://www.cdc.gov/nchhstp/healthdisparities/africanamericans.html>

²⁴ CDC. HIV/AIDS: HIV among African American gay and bisexual men. Updated 2017 Feb 1. Available from <http://www.cdc.gov/hiv/group/msm/bmsm.html>

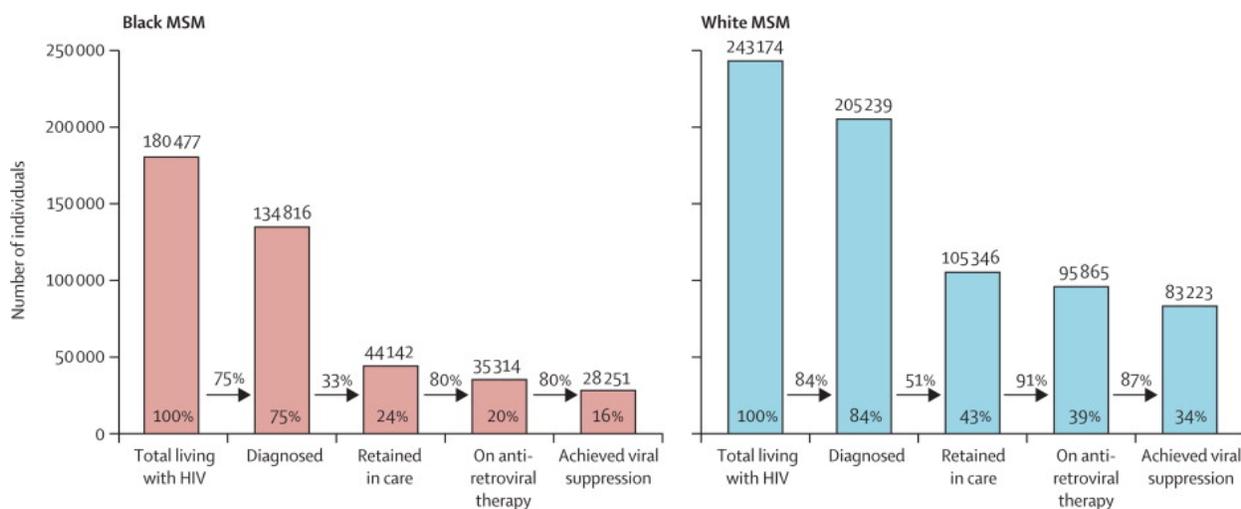
²⁵ CDC. HIV/AIDS: HIV among gay and bisexual men. Updated 2017 Sep 27. Available from <http://www.cdc.gov/hiv/group/msm/>

²⁶ CDC. HIV/AIDS: HIV among African American gay and bisexual men. Updated 2016 Feb 4. Accessed from <http://www.cdc.gov/hiv/group/msm/bmsm.html>

²⁷ Millett GA, Flores SA, Peterson JL, and Bakeman R. Explaining disparities in HIV infection among Black and White men who have sex with men: a meta-analysis of HIV risk behaviors. *AIDS*. 2007;21(15):2083-91.

Regardless of these considerations, the HIV-related outcomes for black MSM are worse than those for white MSM along every step of the HIV Care Continuum (see Figure 3).²⁸ At 16%, the rate of viral suppression among black MSM is only about half of the overall national rate (30%).²⁹ Among those with diagnosed HIV infection, an estimated 47% of white MSM are virally suppressed, as opposed to 28% of black MSM and 37% of Hispanic MSM.³⁰ Black MSM have the highest percentage (11.8%), when compared to other populations of MSM, of PLWH who have never attained viral suppression—over 3 times the percentage of white MSM (3.7%).³¹

Figure 3: Estimated HIV Care Continuum for Black MSM vs. White MSM, 2009-2010³²



Even though deaths among PLWH have been declining since the availability of ART medications, the death rate per 1,000 PLWH in 2012 for black people (20.5) was higher than the rates for white people (18.1) and Hispanics/Latinos (13.9).³³

Although Hispanics/Latinos make up only 18% of the U.S. population, they accounted for nearly one quarter of all new HIV diagnoses in 2015.³⁴ Hispanics/Latinos are more likely than black people or white people to be diagnosed with AIDS within three years of their HIV diagnosis.³⁵ Moreover, Hispanics who only speak Spanish are less likely to be adequately informed about the disease and

²⁸ Rosenberg ES, Millett GA, Sullivan PS, del Rio C, and Curran JW. Understanding the HIV disparities between Black and White men who have sex with men in the USA using the HIV Care Continuum: a modelling study. *Lancet HIV*. 2014;1(3):e112-e118.

²⁹ CDC. Understanding the HIV Care Continuum. 2014 December. Available from <http://www.cdc.gov/hiv/pdf/library/factsheets/understanding-hiv-care-continuum.pdf>

³⁰ Hall HI, Holtgrave DR, Tang T, and Rhodes P. HIV transmission in the United States: considerations of viral load, risk behavior, and health disparities. *AIDS Behav*. 2013;17(5):1632-6.

³¹ Nicole Crepez, Tian Tang, Gary Marks I, Irene Hall Viral-load Dynamics Among Persons with Diagnosed HIV—United States, 2014. *Conference on Retroviruses and Opportunistic Infections, Abstract Book*. (2017) <http://www.croiconference.org/sites/default/files/uploads/croi2017-abstract-eBook.pdf>

³² Rosenberg ES, Millett GA, Sullivan PS, del Rio C, and Curran JW. Understanding the HIV disparities between Black and White men who have sex with men in the USA using the HIV Care Continuum: a modelling study. *Lancet HIV*. 2014;1(3):e112-e118.

³³ Siddiqi AA, Hu X, and Hall HI. Mortality among Blacks or African Americans with HIV infection—United States, 2008-2012. *MMWR*. 2015;64(4):81-86

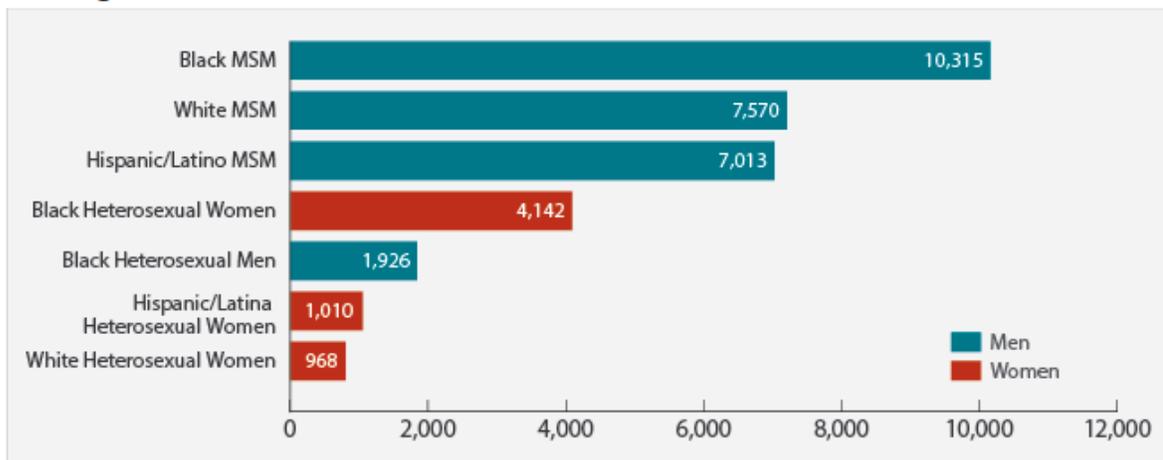
³⁴ CDC. HIV/AIDS: HIV among Hispanics/Latinos. Updated 2017 Sept 26. Available from <http://www.cdc.gov/hiv/group/racialethnic/hispaniclatinos/index.html>

³⁵ Shouse RL, Kajese T, Hall HI, and Valleroy LA. Late HIV testing - 34 states, 1996-2005. *MMWR*. 2009;58(24): 661-665.

continue to be disproportionately affected by HIV, when compared with women of other races/ethnicities. Of the total number of estimated new HIV infections among women in 2014, 61% (4,524) were in African Americans, 19% (1,431) were in white people, and 15% (1,131) were in Latinas.

Figure 5: Estimates of New HIV Infections in the United States for the Most-Affected Subpopulations, 2014⁴²

HIV Diagnoses in the United States for the Most-Affected Subpopulations, 2015



*Subpopulations that represent 2% or less of HIV diagnoses are not represented in this graphic.

Recent data about lifetime risk also show a significantly higher likelihood of HIV diagnosis for African American or Hispanic women than for a white woman.⁴³ 1 in 880 white women will be diagnosed with HIV in her lifetime, compared to 1 in 227 Latina women, and 1 in 48 African American women. This means that Latina women are 4 times more likely to be diagnosed with HIV than white women, and African American women are 18 times more likely to be diagnosed with HIV than white women.

A recent study found that for women, being African-American is strong predictor of sustained high levels of viral load.⁴⁴ In females who fall into the transmission category of heterosexual contact and have been diagnosed with HIV, African-American women have the highest rates of PLWH not having reached viral suppression (12.3%), while white women have the lowest rates (6.8%). Latina women fall in between the two groups on this spectrum, with a rate of 8.2%.⁴⁵

⁴² CDC. HIV/AIDS: HIV among women. Updated 2017 Mar 10. Available from <http://www.cdc.gov/hiv/group/gender/women/>

⁴³ CDC/NCHHSTP. 2016 conference on retroviruses and opportunistic infections--CROI graphics: lifetime risk of HIV diagnosis in the United States. Updated 2016 Feb 24. Available from <http://www.cdc.gov/nchhstp/newsroom/2016/croi-2016.html>

⁴⁴ Seble Kassaye, Cuiwei Wang, Jeff Collmann, Tracey Wilson, Kathryn Anastos, Mardge H. Cohen, Ruth Greenblatt, Joel Milam, Steven Gange, Michael Plankey. Longitudinal Viral Trajectory Among Women in the Women's Interagency HIV Study. *Conference on Retroviruses and Opportunistic Infections, Abstract Book*. (2017) <http://www.croiconference.org/sites/default/files/uploads/croi2017-abstract-eBook.pdf>

⁴⁵ Nicole Crepaz, Tian Tang, Gary Marks, Irene Hall. Viral-load Dynamics Among Persons with Diagnosed HIV—United States, 2014. *Conference on Retroviruses and Opportunistic Infections, Abstract Book*. (2017) <http://www.croiconference.org/sites/default/files/uploads/croi2017-abstract-eBook.pdf>

3) Youth

In 2010, Youth (aged 13 to 24) made up 17% of the U.S. population, but accounted for an estimated 26% (12,200) of all new HIV infections.⁴⁶ More recently, Youth accounted for an estimated 22% (8,804) of all new HIV infections in 2015.⁴⁷ In other words, more than one in five new HIV diagnoses were among persons aged 13 to 24 years. An estimated 1,489 Youth received AIDS diagnoses in 2015, accounting for 8% of all AIDS diagnoses that year.

At the end of 2013, there were an estimated 54,200 youth living with HIV in the United States; of these, 24,100 were living with undiagnosed HIV infection.⁴⁸ This means that 44.4% of Youth living with HIV in the United States do not know they are infected, compared to the overall average of 15.0% of people of all ages living with undiagnosed HIV.⁴⁹

Black and Hispanic/Latino Youth are disproportionately affected by HIV (see Figure 6). Even more strikingly, young black people (aged 13 to 19) were 64% of young people diagnosed with HIV in 2015, yet only represented 14% of the total youth population in the United States.⁵⁰ CDC data indicate that among PLWH alive at the end of 2014, 48.1% of Youth had viral loads of <200 copies/mL, as compared to 61.1% of individuals over 55 and the overall average of 57.9% of individuals across all ages.⁵¹ Among PLWH with one or more viral load tests, 74.1% of Youth were virally suppressed, as compared to 85.4% of individuals over 55 and the overall average of 80% of individuals across all ages. These numbers indicate a clear disparity in viral suppression that Youth face.⁵²

Young MSM are also disproportionately affected by HIV, particularly young MSM of color. Young MSM accounted for 80% of new HIV infections among Youth in 2014 and 27% of new infections among all MSM in 2010.⁵³ Moreover, from 2005 to 2014, HIV diagnoses among young MSM increased to approximately 87% among black people and Hispanics/Latinos, and 56% among white people. Data (2010-2014) from young MSM show that this increase in HIV diagnoses has stabilized among black people and white people and slowed to 16% among Hispanics/Latinos.

⁴⁶ Reisner SL, Veters R, White JM, Cohen EL, LeClerc M, Zaslow S, et al. Laboratory-confirmed HIV and sexually transmitted infection seropositivity and risk behavior among sexually active transgender patients at an adolescent and young adult urban community health center. 2015. *AIDS Care*. 2015;27(8):1031-1036.

⁴⁷ CDC. HIV/AIDS: HIV among youth. Updated 2017 Oct 26. Available from <http://www.cdc.gov/hiv/group/age/youth/>

⁴⁸ CDC. HIV/AIDS Surveillance Report: Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data—United States and 6 Dependent Areas, 2014. Vol. 21, No. 4. Available from https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-22-2.pdf?_sm_au=iVV577rJkFPpH4TQ.

⁴⁹ Ibid.

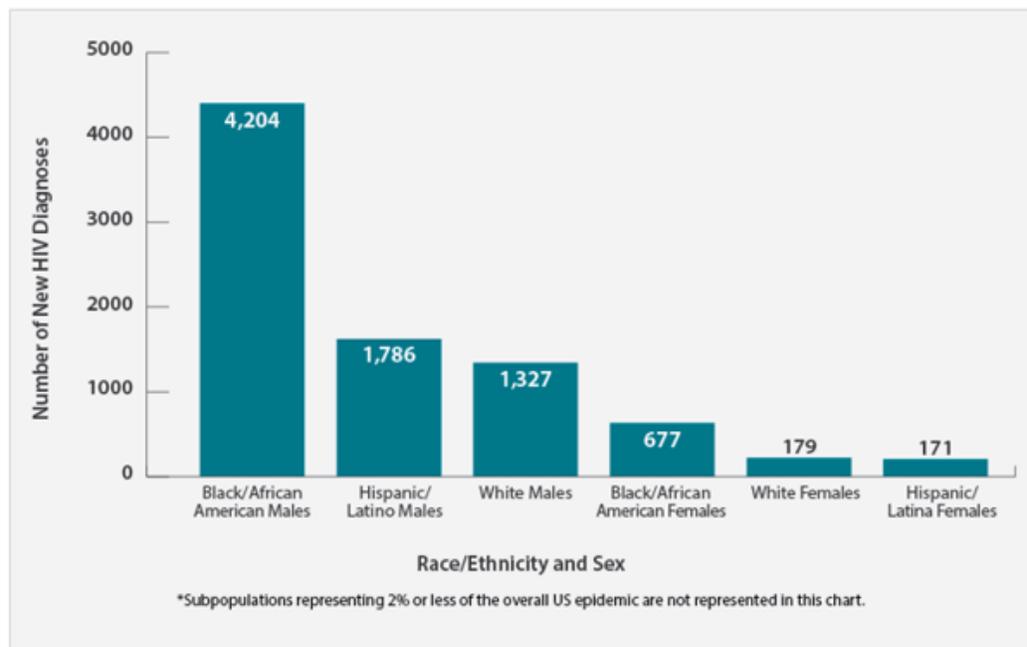
⁵⁰ CDC. HIV/AIDS Resource Library Slide Sets: HIV surveillance in adolescents and young adults (through 2015). Updated 2017 July 27. Available from <http://www.cdc.gov/hiv/library/slideSets/index.html>

⁵¹ CDC. HIV/AIDS Surveillance Report: Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data—United States and 6 Dependent Areas, 2015. Vol. 22, No. 2. Available from <http://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-22-2.pdf>

⁵² Ibid.

⁵³ CDC. HIV/AIDS: HIV among youth. Updated 2016 Apr 27. Available from <http://www.cdc.gov/hiv/group/age/youth/>

Figure 6: Estimated New HIV Diagnoses Among Youth Aged 13-24 by Race/Ethnicity and Sex, United States 2015⁵⁴



In 2014, Zandoni and Mayer found that the HIV Care Continuum for Youth was significantly different from the overall national Continuum (see Figure 7).⁵⁵ For example, only about 41% of youth aged between 13 to 29 who are living with HIV are diagnosed,⁵⁶ which is less than half the overall rate of HIV diagnosis (87%).⁵⁷

Figure 7: HIV Care Continuum for Youth, Ages 13 to 29⁵⁸

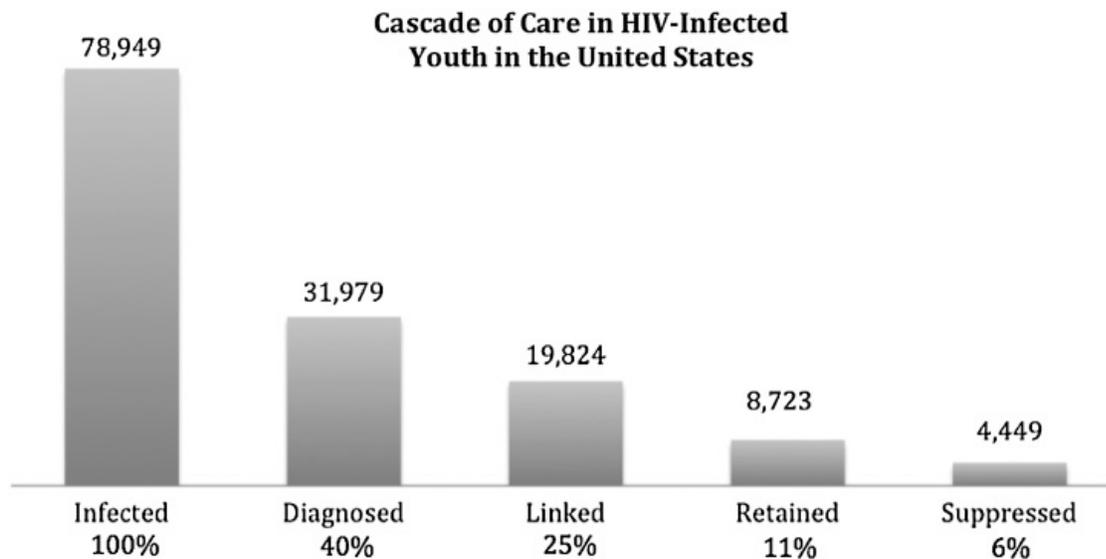
⁵⁴ CDC. HIV/AIDS: HIV among youth. Updated 2017 Oct 26. Available from <http://www.cdc.gov/hiv/group/age/youth/>

⁵⁵ Zandoni BC and Mayer KH. The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities. *AIDS Patient Care STDS*. 2014;28(3):128-35.

⁵⁶ Zandoni BC and Mayer KH. The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities. *AIDS Patient Care STDS*. 2014;28(3):128-35.

⁵⁷ CDC. HIV/AIDS: basic statistics. Updated 2016 March 16. Available from <http://www.cdc.gov/hiv/basics/statistics.html>

⁵⁸ Zandoni BC and Mayer KH. The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities. *AIDS Patient Care STDS*. 2014;28(3):128-35.



Addressing the low percentage of those who are aware of their diagnosis is important because more than 50% of new HIV infections occur as a result of the 21% of people who do not know they are infected.⁵⁹ Perhaps the most striking are the data that suggest that less than 6% of Youth living with HIV are virally suppressed,⁶⁰ compared to the overall viral suppression rate of 30%.⁶¹ Drop-offs at all points in the Care Continuum contribute to this low rate of viral suppression.⁶² Hall and colleagues corroborated these results by finding that the rates for each element on the Care Continuum increase with each older age group (outcomes are worst for those ages 13-24 and best for those ages 55-64) (see Figure 8).⁶³ Recent data from the RWHAP also indicate a discrepancy in the viral suppression rates in those who had at least one outpatient ambulatory medical care visit during the calendar year and at least one viral load reported between youth aged 13-24, at 65%, and the all RWHAP clients, at 81%.⁶⁴

Figure 8: HIV Care Continuum per Age Group⁶⁵

⁵⁹ Zanoni BC and Mayer KH. The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities. *AIDS Patient Care STDS*. 2014;28(3):128-35.

⁶⁰ Zanoni BC and Mayer KH. The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities. *AIDS Patient Care STDS*. 2014;28(3):128-35.

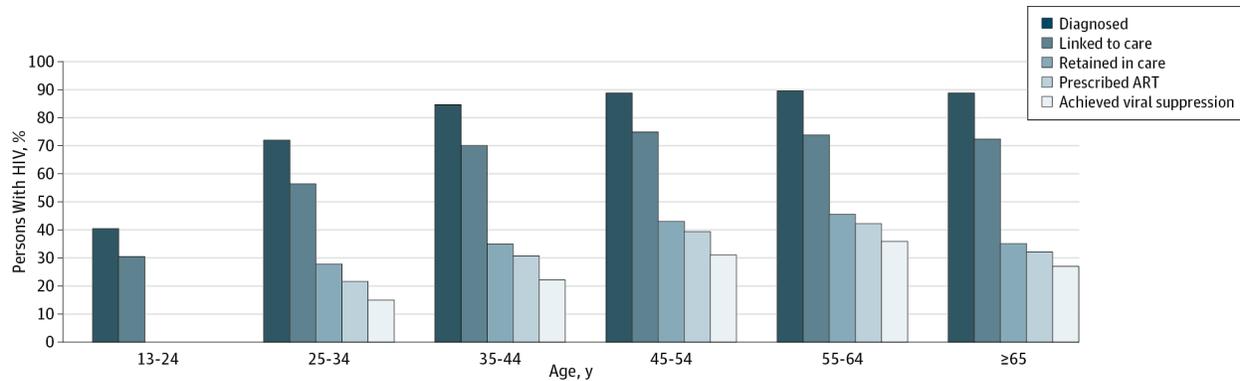
⁶¹ CDC. Understanding the HIV Care Continuum. 2014 December. Available from <http://www.cdc.gov/hiv/pdf/library/factsheets/understanding-hiv-care-continuum.pdf>

⁶² Zanoni BC and Mayer KH. The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities. *AIDS Patient Care STDS*. 2014;28(3):128-35.

⁶³ Hall HI, Frazier EL, Rhodes P, Holtgrave DR, Tang T, Gary KM, et al. Differences in human immunodeficiency virus care and treatment among subpopulations in the United States. *JAMA Intern Med*. 2013;173(14):1337-44.

⁶⁴ HRSA. Ryan White HIV/AIDS Program State Profiles. The United States—The Ryan White HIV/AIDS Program Client Clinical Outcomes. Updated 2017 Feb 28. Available from <https://hab.hrsa.gov/stateprofiles/Client-Clinical-Characteristics.aspx#chart2>

⁶⁵ Hall HI, Frazier EL, Rhodes P, Holtgrave DR, Tang T, Gary KM, et al. Differences in human immunodeficiency virus care and treatment among subpopulations in the United States. *JAMA Intern Med*. 2013;173(14):1337-44.



4) Transgender People

Transgender communities in the United States are among the groups at highest risk for HIV infection. The term gender identity refers to a person’s internal identification with a gender, and transgender refers to a person whose gender identity does not conform to a binary classification of gender based on biological sex, external genitalia, or their sex assigned at birth.⁶⁶ Most studies define transgender individuals into a binary of either transgender woman/trans feminine or transgender man/trans masculine. Transgender woman refers to an individual who was assigned a male sex at birth, but chooses to express their gender as female or along the feminine spectrum. Conversely, transgender man refers to an individual who was assigned a female sex at birth, but chooses to express their gender as male or along the masculine spectrum.⁶⁷ Reliable data on transgender individuals can be hard to attain because many providers do not have clear methods by which to categorize them. There is a dearth of information about the HIV epidemic within the transgender man population.⁶⁸

In an analysis of HIV testing events at CDC sites between 2009 and 2011, transgender people were found to have much higher percentages of HIV-positive test results (2.4%), compared to both cisgender males (0.9%) and females (0.2%).⁶⁹ Globally, it is estimated that around 19% of transgender women are living with HIV; they are also 49 times more likely to acquire HIV than all adults.⁷⁰

Although transgender people do not make up a large proportion of PLWH, the prevalence of HIV within the transgender community is disproportionately high.⁷¹ In 2016, the Williams Institute estimated that roughly 0.6% of the total U.S. adult population identifies as transgender (men or

⁶⁶ CDC. HIV/AIDS: HIV among transgender people. Updated 2017 Aug 3. Available from <http://www.cdc.gov/hiv/group/gender/transgender/>

⁶⁷ Poteat, Tonia & Scheim, Ayden & Xavier, Jessica & Reisner, Sari & Baral, Stefan.. Global Epidemiology of HIV Infection and Related Syndemics Affecting Transgender People. *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2016. 72 10.1097/QAI.0000000000001087.

⁶⁸ Ibid.

⁶⁹ Habarta N, Wang G, Mulatu MS, and Larish N. HIV testing by transgender status at Centers for Disease Control and Prevention–funded sites in the United States, Puerto Rico, and US Virgin Islands, 2009–2011. *Am J Public Health*. 2015;105(9):1917-25.

⁷⁰ UNAIDS. The Gap Report 2014: people living with HIV. 2014 October 7. Available from <http://www.unaids.org/en/resources/campaigns/2014/2014gapreport/gapreport>

⁷¹ Office of National AIDS Policy. National HIV/AIDS strategy: updated to 2020. July 2015. Available from <https://www.whitehouse.gov/administration/eop/onap/>

women).⁷² However, Mizuno and colleagues found that 1.3% of PLWH receiving care in the United States self-identified as transgender women, indicating a disproportionate HIV prevalence within this population.⁷³

Some studies indicate that the rate of HIV prevalence among transgender women could be as high as 28%,⁷⁴ compared to an overall HIV prevalence rate in the United States of approximately 0.4 to 0.9%.⁷⁵ Higher percentages of newly identified HIV-positive test results were found among black transgender women (51%) than among white (11%) or Latina (29%) transgender women.⁷⁶

Furthermore, compared to cisgender women, transgender women were disproportionately likely to be diagnosed with AIDS within three months of HIV diagnosis.⁷⁷ Although MSM and transgender women have similar CD4 counts at diagnosis, transgender women were found to have delayed linkage to care and lower viral suppression rates than MSM.⁷⁸ Data from 2014 indicate that viral suppression in transgender people who have had at least one outpatient ambulatory medical care visit during the calendar year and at least one viral load reported, the rate of viral suppression is 74%, compared to that of cisgender men (82%) and women (80%)⁷⁹.

Williamson found that healthcare providers and systems are often underequipped in their ability to provide effective care to those who identify as transgender.⁸⁰ A provider who is not attuned to the particular needs of this subpopulation is highly prone to inadvertently creating an unreceptive environment for a patient seeking care. This environment may lower the likelihood of a patient staying in care, which ultimately results in poorer health outcomes. Mizuno and colleagues found that transgender women have significantly lower ART dose adherence and durable viral suppression compared to non-transgender men, even though they have similar rates in terms of receipt of care, treatment, and supportive services.⁸¹ Transgender women have higher unmet needs for basic services, like food and housing, which may exacerbate already poor outcomes.

An important consideration is that there have been very few efforts to address HIV-related disparities among transgender men (female-to-male transgender persons). In a systematic literature

⁷² Flores AR, Herman JL, Gates GJ, Brown TNT. How many adults identify as transgender in the United States? *The Williams Institute*. June 2015. Available from <http://williamsinstitute.law.ucla.edu/wp-content/uploads/How-Many-Adults-Identify-as-Transgender-in-the-United-States.pdf>

⁷³ Mizuno Y, Frazier EL, Huang P, and Skarbinski J. Characteristics of transgender women living with HIV receiving medical care in the United States. *LGBT Health*. 2015;2(3):228-234.

⁷⁴ Herbst JH, Jacobs ED, Finlayson TJ, McKleroy VS, Neumann MS, Crepaz N, et al. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: a systematic review. *AIDS Behav*. 2008;12(1):1-17.

⁷⁵ UNAIDS. Countries: United States of America—HIV and AIDS estimates (2012). Available from <http://www.unaids.org/en/regionscountries/countries/unitedstatesofamerica> Accessed June 16 2016.

⁷⁶ CDC. HIV/AIDS: HIV among transgender people. Updated 2017 Aug 3. Available from <http://www.cdc.gov/hiv/group/gender/transgender/>

⁷⁷ Fennie KP, Trepka MJ, Maddox LM, Lutfi K, and Lieb S. Comparison of individual and area level factors between HIV-infected cisgender and transgender individuals in Florida (2006–2014). *AIDS and Behav*. 2016 Feb: epub ahead of printing.

⁷⁸ Wiewel EW, Torian LV, Merchant P, Braunstein SL, and Shepard CW. HIV diagnoses and care among transgender persons and comparison with men who have sex with men: New York City, 2006–2011. *Am J Public Health*. 2016;106(3):497-502.

⁷⁹ HRSA. Ryan White HIV/AIDS Program State Profiles. The United States—The Ryan White HIV/AIDS Program Client Clinical Outcomes. Updated 2017 Feb 28. Available from <https://hab.hrsa.gov/stateprofiles/Client-Clinical-Characteristics.aspx#chart2>

⁸⁰ Williamson C. Providing care to transgender persons: a clinical approach to primary care, hormones, and HIV management. *J Assoc Nurses AIDS Care*. 2010;21(3):221-9.

⁸¹ Mizuno Y, Frazier EL, Huang P, and Skarbinski J. Characteristics of transgender women living with HIV receiving medical care in the United States. *LGBT Health*. 2015;2(3):228-234.

review conducted by Herbst and colleagues, it was found that, of 29 identified HIV-related studies of transgender peoples, only 5 included data specifically about transgender men.⁸²

Due to the low percentage of those who self-identify as transgender in the United States, interventions focused on this population have historically been quite limited.⁸³ However, the high HIV prevalence within this population indicates that reducing this disparity would have a far-reaching impact on HIV-related mortality and morbidity among this underserved community.

⁸² Herbst JH, Jacobs ED, Finlayson TJ, McKleroy VS, Neumann MS, Crepaz N, et al. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: a systematic review. *AIDS Behav.* 2008;12(1):1-17.

⁸³ Office of National AIDS Policy. National HIV/AIDS strategy: updated to 2020. July 2015. Available from <https://www.whitehouse.gov/administration/eop/onap/>