



**BLACK WOMEN'S**  
HEALTH IMPERATIVE

# HIV/AIDS Policy Agenda FOR *Black Women*



## ACKNOWLEDGMENTS

### PREPARED BY

Linda Goler Blount, MPH  
Tammy Boyd, JD, MPH  
Kineta Sealey, JD

### CONTRIBUTORS

Venita Ray  
*Deputy Director*  
Positive Women's Network - USA

Breanna Diaz  
*Policy Director*  
Positive Women's Network - USA

Kelly Flannery  
*If/When/How Reproductive Justice - HIV Fellow*  
Positive Women's Network-USA

Valerie L. Rochester  
*Vice President for Program Strategy*  
AIDS United

Demisha Burns, PhD, MSW  
*Policy and Advocacy Manager*  
Women Organized to Respond to Life-Threatening Diseases (WORLD)

Sequoia Ayala, JD  
*Policy Counsel/Director of Policy and Advocacy*  
SisterLove, Inc.

Jackie Tosto, Esq.  
*If/When/How Law and Policy Fellow*  
SisterLove, Inc.

Chanda Nicole Holsey, PhD, MPH  
*Founder/Principal*  
HALO for Families

### PROOFREADER

Laura J. Nadel, Radiance Communications

### DESIGN

Dana Magsumbol Design

### PHOTOGRAPHY

Eli Turner, istock and adobe stock

### EDITORS

Nancy Lee, MD  
Valerie L. Rochester, MPA  
Andrea Collier

### BLACK WOMEN'S HEALTH IMPERATIVE STAFF

Linda Goler Blount, MPH  
*President & CEO*

Tammy Boyd, JD, MPH  
*Chief Policy Officer & Counsel*

Kineta Sealey, JD  
*Legal and Policy Fellow*

Angela Ford, PhD, MSW  
*Chief Program Officer*

Ann McMikel  
*Chief Development Officer*

Monica Coleman  
*Chief Communications Officer*

Zsanai Epps, MPH, CHES  
*Manager of Special Projects*

Dena Smith  
*Executive Administrator*

### ON OUR OWN TERMS STEERING COMMITTEE

AIDS United - *Washington, DC*  
Black Women's Blueprint - *Brooklyn, NY*  
National Black Leadership Commission on AIDS, Inc. *New York, NY*  
New York Transgender Advocacy Group - *New York, NY*  
Positive Women's Network, Inc. - *Oakland, CA*  
Women Organized to Respond to Life - Threatening Diseases, WORLD - *Oakland, CA*

### ON OUR OWN TERMS ADVISORY COUNCIL

The Afiya Center - *Dallas, TX*  
Black Women for Wellness - *Los Angeles, CA*  
Center for Black Women's Wellness - *Atlanta, GA*  
emPOWERed Legacies - *Winter Haven, FL*  
Let's BeeHIVE! - *Orlando, FL*  
My Brother's Keeper - *Jackson, MS*  
National Black Justice Coalition - *Washington, DC*  
Sister Love - *Atlanta, GA*  
Sister Reach - *Memphis, TN*  
Sisters Together and Reaching, Inc. (STAR) - *Baltimore, MD*  
Texas Black Women's Initiative - *Houston, TX*  
The Women's Collective - *Washington, DC*



The Agenda was sponsored with the generous support of Gilead Sciences.

# Contents

President's Letter .....	2
Executive Summary .....	4
<b>I. PREVENTION .....</b>	<b>6</b>
A. Stigma and Discrimination .....	7
B. HIV Testing .....	8
C. Knowledge of and Access to PrEP .....	9
D. Injection Drug Use .....	10
E. Young People .....	11
F. Historically Black Colleges and Universities .....	12
G. Reproductive Health .....	15
<b>II. ACCESS TO CARE .....</b>	<b>16</b>
A. Health Care Reform .....	18
B. Medicaid .....	19
C. Medicare .....	20
D. Ryan White HIV/Aids Program (RWHAP) .....	21
E. Nondiscrimination Protections .....	21
F. Online Pharmacies .....	22
G. Global Considerations .....	23
<b>III. LIVING WITH HIV .....</b>	<b>24</b>
A. Housing .....	25
B. Employment .....	27
C. HIV Criminalization .....	28
D. Immigration .....	33
<b>IV. AWARENESS DAYS .....</b>	<b>38</b>
<b>V. GLOSSARY OF TERMS .....</b>	<b>39</b>
<b>VI. ENDNOTES .....</b>	<b>40</b>
<b>VII. ABOUT ON OUR OWN TERMS .....</b>	<b>44</b>





Dear Supporters:

In 2018, Black Women's Health Imperative (BWHI) released its comprehensive policy agenda, ***Black Women Vote: National Health Policy Agenda***, to build upon Black women's political influence, ballot power, and commitment to civic participation. In this document, BWHI discusses critical issues that impact Black women's health. Among those issues is Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS).

BWHI also established On Our Own Terms (OOOT), a national collaboration of Black women's organizations that works to establish key priorities and proactive approaches to improve sexual health generally, and HIV outcomes specifically, for Black women. OOOT advocates for evidence-based practices and cross-sector collaborations, and strengthening of community assets, while highlighting our mutual abilities to deliver innovative solutions and make a lasting investment in the health and wellness of Black women and other women of color.

Black men and women have been disproportionately impacted by HIV and AIDS since the epidemic's beginning, and that disparity has deepened over time. While representing only 12 percent of the United States population, Black Americans accounted for almost half (42 percent, or 476,100) of the estimated 1.1 million people living with HIV (PLHIV) – both diagnosed and undiagnosed – and almost half (44 percent) of those diagnosed with HIV in 2016.<sup>1</sup> African American and Latino gay and bisexual men are the most affected, followed by heterosexual Black women.<sup>2</sup> According to the latest available data from the Centers for Disease Control and Prevention (CDC), Black women currently account for more than 60 percent of all HIV diagnoses among women.<sup>3</sup>

While Black Americans continue to be the most impacted by HIV and AIDS of any racial/ethnic group in the nation, prevention efforts and improved access to care have led to decreases in the number and rate of new transmissions and have improved health outcomes for PLHIV. Recent data indicate some encouraging trends, including declining new HIV diagnoses for Blacks overall, especially among women.<sup>4</sup> However, given the epidemic's disproportionate impact on the Black community, a continued focus on the prevention of new transmissions and access to treatments is critical to addressing, and hopefully ending, HIV in the U.S.



BWHI is committed to addressing the critical issue of HIV and AIDS among Black women and girls, both domestically and internationally. As you will read, our HIV and AIDS policy agenda is focused on four key areas: (1) addressing the stigma that can attach to even the mere proximity to HIV and AIDS; (2) prevention of future HIV transmissions; (3) access to comprehensive treatment for Black women living with HIV; and (4) the provision of essential supports, beyond medical treatment, that target the well-being of Black women who are navigating living with HIV and AIDS. Under each key area, BWHI includes a thorough discussion regarding the key issues facing Black women today, with concrete policy recommendations to help move toward real solutions.

With a better understanding of how to effectively prevent and treat HIV, it is more important than ever to address the root causes of higher rates of HIV in Black women. In short, Black women must finally be a priority in policy directed toward the prevention of HIV and other sexually transmitted infections (STIs).

In addition to making sure that issues unique to Black women are addressed in health policy discussions, BWHI is mindful that policy *solutions* – specific and actionable – are the ultimate goal. In working to develop solutions to the health challenges facing Black women, BWHI is partnering with stakeholders – community-based organizations, elected officials, HIV policy organizations, PLHIV, and women-led organizations – who also want to see Black women achieve optimal health. We invite you to join us in our efforts.

Sincerely,

A handwritten signature in black ink, reading "Linda Goler Blount". The signature is fluid and cursive, with the first name "Linda" being more prominent.

Linda Goler Blount, MPH  
*President and CEO*



## Executive Summary

In the areas of policy and advocacy, the Black Women's Health Imperative (BWHI) evaluates and develops national and state public policies to address the most critical issues facing Black women's health. Among these issues is HIV and AIDS.

BWHI established a strategic partnership – On Our Own Terms (OOOT) – that aligns key priorities and proactive approaches to impact the sexual health and improve HIV outcomes for Black women.

OOOT is a national collaboration of Black women's organizations that combines evidence-based practices, cross-sector collaborations, and strengthening of community assets, while it highlights our mutual abilities to deliver innovative solutions and make a lasting investment in the health and wellness of Black women and other women of color.

This policy agenda makes recommendations for improving the health and wellness of Black women who are living with HIV, and for creating and implementing policies that support preventing the spread of the disease, testing, and early diagnosis.

We believe that, through policies, funding, partnerships, and progress on the medical and scientific fronts, together we can end HIV in the United States.

As such, local, state, and national policy professionals and stakeholders should consider how the various aspects of a person's identity and life circumstances may combine to increase the risk of acquiring HIV and, if acquired, create difficulty in obtaining the services needed to lead a healthy, safe, and productive life. HIV has been part of our lives for more than three decades. Now is the time to eliminate it once and for all.

### ***What is HIV?***

The Human Immunodeficiency Virus (HIV) is a retrovirus that attacks cells that help the body fight infection.<sup>5</sup>

HIV can negatively impact the body's immune system, destroying infection-fighting cells called T-cell lymphocytes, leaving a person living with HIV (PLHIV) highly susceptible to illnesses that the body would otherwise be able to fight off.<sup>6</sup> This is how HIV-positive persons who do

not undergo treatment may develop Acquired Immunodeficiency Syndrome (AIDS), the most advanced stage of HIV.<sup>7</sup>

No cure for HIV currently exists; however, treatment options have advanced greatly. Often, just one pill a day, when taken as prescribed, can reduce the viral load to an undetectable level.<sup>8</sup> This means that PLHIV can potentially live long and healthy lives when they have access to the care they need.

### ***Why Does It Still Matter?***

Initially thought to be a disease that impacts only certain communities,<sup>9</sup> it is now clear that HIV and AIDS can affect anyone, regardless of race, sex, age, gender identity, sexual orientation, location, or socio-economic status, among other demographics.

Despite this knowledge, we are aware that HIV and AIDS thrive in conditions of inequity and injustice. Poverty, joblessness, addiction, incarceration, and discrimination can serve as both causes and effects of behaviors that result in HIV.

According to a Kaiser Family Foundation (KFF) Health Tracking Poll, a larger percentage of Black Americans report being concerned about getting HIV than White Americans.<sup>10</sup> This concern is supported by available data.

Between 2010 and 2016, the number of new HIV transmissions for Black Americans decreased.<sup>11</sup> In addition, between 2008 and 2016, the number of new transmissions among Black women fell by nearly 40 percent.<sup>12</sup> The decline in new HIV diagnoses in the U.S. suggests that the myriad of HIV prevention strategies is working.

Even with medical advances, new HIV diagnoses still number almost 40,000 each year,<sup>13</sup> and as many as one in seven individuals are unaware that they are living with HIV.<sup>14</sup> As compared to other races/ethnicities, Black Americans account for a higher percentage of new HIV diagnoses.<sup>15</sup> In 2017, Black Americans, who represent 13 percent of the U.S. population, accounted for 43 percent of the newly diagnosed (16,694).<sup>16</sup> In addition, for every 100,000 Black Americans, the rate of new diagnoses was eight times higher than the rate for

White Americans and more than double the rate for Latinos/Hispanics.<sup>17</sup>

While the number of new HIV transmissions among Black women decreased by more than 20 percent in the period 2010 to 2016, in 2016, the 4,560 Black women diagnosed with HIV represented 61 percent of HIV diagnoses among all women in the U.S. that year.<sup>18</sup> Significantly, 1 in 48 Black women in the U.S. will acquire HIV in her lifetime.<sup>19</sup> In addition, while the available data for Black transgender women are lacking, current data strongly suggest that the risk of HIV for Black trans women is even higher, as it is estimated that 44 percent of Black trans women are living with HIV.<sup>20</sup> Further, from 2009 to 2014, Black trans women accounted for 84 percent of all HIV diagnoses among trans people in the U.S.<sup>21</sup> Consequently, policies and funding that support prevention strategies are critical in the fight to end HIV.

#### ***HIV and the South***

Although the rates of HIV have decreased nationally, the rates of HIV in the South – particularly among people of color – are still prevalent. Nine states in the Deep South account for 28 percent of the U.S. population, yet they account for 40 percent of new HIV diagnoses.<sup>22</sup> Among all women who were diagnosed with HIV in 2017, 59 percent were African American.<sup>23</sup> As of 2017, there are 113,784 women living with HIV (WLHIV) in the South;<sup>24</sup> 37,155 cases were in Georgia alone.<sup>25</sup> Of those 37,155 cases, almost 20 percent is female.<sup>26</sup> In New Orleans 2,353 women currently are living with HIV.<sup>27</sup> In Atlanta, the rate of contracting HIV for a Black woman is 15 times higher than that of a White woman;<sup>28</sup> in Louisiana, the rate is 10 times more likely.<sup>29</sup> There were 1,597 new HIV diagnoses in Georgia in 2017, which was the highest number since 2013, and 16.8 percent of those new cases were female.<sup>30</sup> Further, Georgia has the second highest rate of Black women and girls living with HIV who have progressed to AIDS.<sup>31</sup> Although women, particularly Black women, are often overlooked in the HIV discussion, Black women account for 75 percent of all women living with HIV in Georgia,<sup>32</sup> where in Louisiana there were more new HIV diagnoses among Black women in 2014 than 2001.<sup>33</sup> The myth that HIV is

a “gay man’s disease” has “framed societal and individual understanding of risk and relevance in ways that keep women from engaging in prevention, accessing care, and impacts research funding, and policy decisions.”<sup>34</sup> The lack of awareness also furthers stigma, and many women avoid getting tested or treated because many feel as though HIV is a “social death”.<sup>35</sup>

Although the rate of new infections for women, including for Black women, has decreased over the years, Black women still are at a higher risk than White women, particularly due to other systemic inequalities they face. One study showed that less than 53 percent of women are fully benefiting from the standard of care, mostly women of color.<sup>36</sup> Neighborhoods with higher rates of poverty, particularly in the South, have fewer health resources that provide HIV preventive services such as testing and sexual health counseling. States such as Georgia have not expanded Medicaid, and many residents are uninsured; this impacts the ability of those living with HIV to receive care.<sup>37</sup> Further, Southern states are still segregated, and areas that are predominantly Black are faced with inequalities including housing and land access.<sup>38</sup> There are also issues such as higher rate of incarceration, lower employment opportunities, and substance abuse.<sup>39</sup> Women find it easier to stay in care when “clinics support their practical, social and emotional needs”.<sup>40</sup>


Community based organizations are a major factor in helping Black women at risk and those living with HIV. There should be greater attention to the social determinants of health (SDoH) and the long standing forces of economic inequality that drive poverty and create our sexual health landscape.<sup>41</sup> Community-based organizations are intersectional, therefore focusing on all the aspects that affect Black women, not just HIV. Understanding the people and the neighborhoods being affected by HIV is imperative to aiding the community in a way that addresses all of the inequalities, such as the need for affordable housing, medically accurate information, and comprehensive services.<sup>42</sup> Helping women overcome these structural barriers allows them to focus on themselves and will lead to more healthy lives.



# PREVENTION







The Centers for Disease Control and Prevention (CDC) defines “HIV stigma” as “negative attitudes and beliefs about persons living with HIV”.<sup>43</sup> However, stigma is much broader, as even persons vulnerable to HIV may face stigma because of their perceived health status or close proximity to persons who are living with HIV. Notably, stigma is different from discrimination, as discrimination is the *behavior* that results from negative attitudes and beliefs.<sup>44</sup> Both stigma and discrimination are harmful to efforts to prevent the transmission of HIV and ensure that all people living with HIV (PLHIV) receive comprehensive health care and services.

### STIGMA AND DISCRIMINATION

Frequently, persons at higher risk of transmitting HIV and those living with HIV internalize stigma.<sup>45</sup> This self-stigma<sup>46</sup> can result in deciding to not get tested,<sup>47</sup> failing to engage in candid conversations regarding risk with sexual partners, and refusing to seek vital medical care and services targeted to persons living with HIV. Further, stigma may result in the spread of misinformation regarding how HIV is transmitted and who is at risk.<sup>48</sup>

In 2017, the Joint United Nations Programme on HIV/AIDS (UNAIDS) released a report that details how stigma and discrimination impact testing and treatment decisions.<sup>49</sup> It found that PLHIV who experience a high degree of HIV-related stigma are more than twice as likely to delay enrollment into care as persons who do not perceive such stigma.<sup>50</sup> In a study of PLHIV in 19 countries, one in five avoided going to a clinic or hospital because they feared they would face stigma or discrimination related to their HIV status.<sup>51</sup> Unfortunately, the UNAIDS report also confirms that these fears are not unfounded, as one in four reported experiencing discrimination in health care settings because of their HIV status, and one in three women experienced discrimination in health care setting relating to their reproductive or sexual health.<sup>52</sup>

**POLICY RECOMMENDATIONS:** BWHI recommends developing interventions to reduce stigma in health care settings. Stigma remains a huge barrier to preventing HIV, and it is linked to low testing rates as well as poor adherence to treatment, particularly among young people. Many PLHIV lose trust in the system and therefore do not seek the appropriate care. Specifically, BWHI recommends:

- Incorporating implicit bias training modules for physicians in HIV Medicine and other health providers;
- Facilitating community engagement forums to educate and raise awareness around the appropriate ways in talking about HIV; and
- Implementing training programs for physicians and health care providers around gender differences which have implications for PLHIV.



## HIV TESTING

HIV testing remains the most critical tool in the fight against HIV. However, most Americans have *never* taken an HIV test.<sup>53</sup> This is despite the CDC recommending that every person age 13-64 should be tested for HIV at least once in their lifetime.<sup>54</sup> In its analysis of 2016-2017 national survey data, the CDC found that:

- Less than 40 percent of persons age 13-64 have been tested for HIV in their lifetimes;<sup>55</sup>
- Less than 30 percent of persons most at risk for HIV have been tested in the last year;<sup>56</sup> and
- In areas with high rates of HIV diagnoses, only a small percentage of persons recommended for annual testing were tested in the past year.<sup>57</sup>

Knowing one's status is important for both PLHIV and for serodiscordant partners. Of the estimated 1.1 million people in the U.S. living with HIV, 14 percent do not know their HIV status.<sup>58</sup> Of Black Americans living with HIV, one in seven are unaware that they are living with HIV.<sup>59</sup> Persons unaware that they are living with HIV are estimated to account for 40 percent of new HIV transmissions in the U.S.<sup>60</sup> Once someone living with HIV knows their status, they may be able to access important medical care that improves their health outcomes. Significantly, those who are able to maintain an undetectable viral load for at least six months can have sexual relationships without any risk of transmitting HIV to their partner.<sup>61</sup>

**POLICY RECOMMENDATIONS:** BWHI recommends funding for more focused research on strategies for reaching and engaging Black women in HIV testing and prevention efforts. BWHI also recommends legislation that would fund efforts to determine best practices for reaching and encouraging Black women, especially those at increased risk of acquiring HIV, to get tested.



# Having Sex? Let's Talk About PrEP!

## Did you know?

**87%** of Black women newly diagnosed with HIV contracted the virus through heterosexual sex.

**1 in 48** Black women in the U.S. will receive an HIV diagnosis in her lifetime.

From 2009 to 2014, **84%** percent of transgender people diagnosed with HIV were transgender women.\*

**PrEP** can reduce your risk of HIV infection by **more than 90%.**

## Protect yourself from HIV infection! PrEP yourself with these simple steps:

- Get tested
- Take one pill each day
- Use condoms always
- Take charge of your sexual health to stay HIV negative

**PrEP** is part of your HIV prevention toolkit that includes getting tested and being aware of your sexual health.

## KNOWLEDGE OF AND ACCESS TO PrEP

Pre-Exposure Prophylaxis (PrEP) is an HIV-prevention strategy that can be used by both men and women. It is estimated that, when taken daily as directed, PrEP reduces the risk of sexually acquiring HIV by more than 90 percent and reduces the risk of acquiring HIV for those who inject drugs by more than 70 percent.<sup>62</sup>

Gilead Sciences, a pharmaceutical company, is currently the only provider of PrEP, marketed under the name Truvada. Recently, a Food and Drug Administration (FDA) advisory panel overwhelmingly voted 16-2 to recommend Descovy – the fixed-dose combination of emtricitabine and tenofovir alafenamide (F/TAF) – as PrEP, to reduce HIV transmission in men who have sex with men (MSM) and transgender women.<sup>63</sup> However, the FDA's Antimicrobial Drugs Advisory Committee split 8-10 on whether to recommend a PrEP indication for F/TAF for cisgender women due to Gilead not having sufficiently inclusive trials.<sup>64</sup>

While it is estimated that more than 1 million people are at high risk of contracting HIV, seven years after PrEP's FDA approval, only a fraction of people at significant risk of acquiring HIV are taking the drug daily.<sup>65</sup> Further, in 2016, of the 78,360 persons who filled prescriptions for PrEP in the U.S., women accounted for just 4.7 percent.<sup>66</sup>

Studies and anecdotal evidence strongly suggest that, in 2019, many Black women still do not know about PrEP.<sup>67</sup> Many factors go into the complex problems Black women face when trying to prevent or live with HIV. Even for those aware of the treatment, accessing PrEP is not always easy. PrEP generally is only available by prescription from an authorized medical professional.<sup>68</sup> In November 2015, it was estimated that one in three primary care doctors and nurses had not heard about PrEP.<sup>69</sup> In some cases, health care providers are aware of PrEP but do not prescribe it, requiring patients to have to seek a prescription elsewhere.<sup>70</sup> Further, in many instances, when Black persons see medical professionals, they are not consistently assessed for their risk of HIV.<sup>71</sup> As a result, the available prevention options, such as PrEP, may not be discussed. New U.S. Preventive Services Task Force (USPSTF) guidelines are a positive step, but, because they rely on a provider's risk assessment, they do not address the underlying problem of provider bias when assessing risk.<sup>72</sup>

## **POLICY RECOMMENDATIONS:** BWHI supports efforts to expand awareness of and use of PrEP.

Knowledge and access to PrEP are the keys to increasing the use of the drug by Black women who are at a higher risk of acquiring HIV. To date, campaigns to promote the drug have not been directed to communities of color. This conclusion is supported by surveys that indicate women generally, and Black women specifically, often are not aware of PrEP or its effectiveness as an HIV prevention tool. In addition, health care providers need to be educated regarding PrEP so that they are better able to serve Black female patients for whom PrEP might be a good option. Further, BWHI supports policy proposals that call for safely reducing barriers to accessing PrEP. As such, BWHI, supports S. 1926, the PrEP Access and Coverage Act<sup>73</sup> introduced by Senator Kamala Harris, as the measure, if enacted, would address the PrEP awareness and access concerns discussed herein.



## INJECTION DRUG USE

Persons who inject drugs are at a substantially greater risk of HIV if they share needles with other injection drug users. HIV can survive in a used syringe for up to 42 days.<sup>74</sup> In addition, a person who does not have HIV has a 1 in 160 chance of acquiring HIV every time they use a needle used by someone living with HIV.<sup>75</sup> More than 2,500 new HIV transmissions occur each year among persons who inject drugs.<sup>76</sup>

Syringe exchange programs (SEPs) are a means by which communities can limit the transmission of HIV. Typically, an SEP provides unused syringes free of charge and without a prescription in exchange for used syringes. The programs typically offer treatment for infectious diseases, referrals for substance abuse treatment, and other health-related services. The CDC provides that SEPs are responsible for an estimated 50 percent reduction in HIV transmissions.<sup>77</sup> In 2018, there were 320 SEPs in the U.S.<sup>78</sup> However, a number of states do not presently have an SEP.

For years, federal funding could not be used on an SEP or similar programs.<sup>79</sup> However, this ban was lifted in part in 2016.<sup>80</sup> Opponents of needle exchange programs argue that such programs encourage drug use.<sup>81</sup> Some contend that money spent on SEPs should instead be used to fund treatment programs, while others argue that SEPs actually link injection drug users to treatment.<sup>82</sup>

Black women living with HIV (WLHIV) are most often acquire HIV through heterosexual transmission – the most common transmission route for women overall – and are less likely to acquire through injection drug use than White women.<sup>83</sup>

**POLICY RECOMMENDATIONS:** BWHI supports state legislation that eliminates barriers to the establishment of SEPs. In addition, in those states where SEPs are already legal, BWHI recommends increasing funding for, and expanding the number of, SEPs in non-urban and rural communities, especially in states with high rates of HIV transmission.

## YOUNG PEOPLE

Young adults and adolescents (ages 13 to 24) are significantly impacted by HIV and AIDS. In 2017, young adults and adolescents composed 21 percent of new HIV diagnoses in the U.S.<sup>84</sup> In 2017, 79 percent of young adults and adolescents who received an HIV diagnosis were aged 20 to 24.<sup>85</sup>

Young adults and adolescents who are living with HIV often are not aware of their status. In 2016, of the 50,900 young adults and children living with HIV, only an estimated 56 percent were aware of their status.<sup>86</sup> Compared with other age groups, young adults and children are least likely to be aware of their HIV status.<sup>87</sup> Even though the CDC recommends HIV testing as part of routine health care, more than half of young adults have never been tested for HIV.<sup>88</sup>

Young adults and adolescents living with HIV who do not know their status are not receiving HIV care. As a consequence, young adults and adolescents with HIV are the least likely of any age group to receive HIV care and achieve a suppressed viral load.<sup>89</sup>

State-level sex education programs, where they even exist, are often limited in scope.<sup>90</sup>



- Only 24 states and the District of Columbia require sex education for youth.
- Thirty-seven states require that abstinence be discussed in sex education programs, and 26 states require that abstinence is emphasized.
- Only 13 states require that the information taught be medically accurate.
- Only 18 states and the District of Columbia require that information regarding contraception be provided in sex education programs.

In addition, in 2017, one-third of federal funding for sexual education programs was spent on abstinence-only education.

**POLICY RECOMMENDATIONS:** BWHI supports and recommends proposals that advocate for comprehensive sex education in middle schools, high schools, colleges, and community programs. Such programs would:

- Normalize conversations regarding sex, refusing to insist on abstinence as the only way to prevent HIV transmission;
- Engage students in conversations regarding how to prevent HIV, including discussions regarding PrEP, condom use, and SEPs;
- Facilitate access to PrEP, condoms, unused syringes/needles, and any other tools that can help prevent the transmission of HIV;
- Educate young adults and adolescents regarding the behaviors and circumstances that may increase their risk of HIV;
- Encourage young adults and adolescents to immediately and regularly get tested if at high risk for HIV;
- Discuss the importance of early diagnosis and immediate and continuous treatment if HIV positive;
- Be sensitive and responsive to the needs of persons in the LGBTQ community, survivors of sexual abuse, and pregnant and parenting youth.

BWHI further recommends eliminating federal funding for abstinence-only education programs and redirecting those funds to support comprehensive sex education programs.



## HISTORICALLY BLACK COLLEGES AND UNIVERSITIES

Black women have disproportionately higher incidence and prevalence rates of HIV and AIDS and higher HIV-related mortality rates as compared to other racial groups. There exists a greater disparity among Southern U.S. states, where only about 38 percent of the total U.S. population lives. The most affected states include Mississippi, Florida, Georgia, and Alabama. The South is also home to a majority of the Historically Black Colleges and Universities (HBCUs). Black students make up at least 40 percent of the population in these high-risk areas – the majority of students being Black women – and HIV prevalence rates in the said areas average about 615.5 per 100,000, which is more than double the U.S. national rate. Social determinants of health (SDoH) contributing to health disparities and adversely affecting Black Americans are also more prevalent in this region. Policies in this region are more likely to hinder proper HIV care without necessarily intending to do so.

Stigma and limited access to care are the most significant barriers to prevention and care measures on HBCU campuses. A recent study to investigate barriers to HIV testing among HBCU students demonstrated that students often opt out of testing due to either being afraid of knowing their HIV status or not wanting to have discussions centering around HIV. These attitudes were associated with a lack of knowledge of prevention and care measures for HIV and AIDS, as well as the unwillingness of some participants to decrease their engagement in high-risk behaviors. Increasing awareness of the



benefits of testing and other HIV and AIDS prevention and care resources is a particularly important approach to decreasing stigma on HBCU campuses.

In order to address this issue, a number of HBCUs have founded their own organizations and partnered with other institutions to educate young adults on HIV and AIDS prevention on their campuses.

- Morehouse College hosted a multi-campus event in 2012, bringing together alumni, representatives of local AIDS service organizations, and students for a panel discussion on HIV, masculinity, and homophobia.<sup>91</sup> In addition, Morehouse has provided education regarding HIV and AIDS prevention every year on World AIDS Day since 2013.
- Mississippi's Jackson State University has a "popular opinion leaders" program in which young men on campus engage their peers in natural, organic conversations about HIV prevention.<sup>92</sup>
- Freshmen at Southern University in Baton Rouge, LA get HIV education as part of a required introductory health course, which hammers home the basic information such as proper condom use and STI prevention facts, and the class can be rehashed to student organizations or in low-stakes environments like residence halls.<sup>93</sup>
- Georgia's Fort Valley State University has instituted gender-specific campaigns that convey positive examples of sexual responsibility.<sup>94</sup>
- North Carolina Central University in Durham has a social media effort that delivers HIV prevention advice to students through Twitter.<sup>95</sup>
- Norfolk State University in Virginia promoted its gender-specific HIV prevention and awareness program by offering \$20 Visa gift cards to students who attend.<sup>96</sup>

Howard University's HBCU-HIV Prevention Project (H2P) is another HBCU-led effort which was recently implemented with the goal of increasing knowledge and awareness of the importance and associated risks of HIV prevention services, counseling, and post-exposure treatment (ARVs) among students and health care providers. The intervention targeted 868 students from three HBCUs (with their consent) and a total of 237 providers. By the end of the intervention, there was a positive change in attitude and beliefs among the students regarding the efficacy of PrEP and other HIV prevention and treatment methods. This was reflected in the recorded significant increase in the number of students who reported getting tested for HIV and AIDS and using condoms during sexual intercourse. There was also a significant decrease in reported risky behaviors, such as drug and alcohol use, prior to sexual intercourse. About 80 percent of the providers who participated in the intervention demonstrated an increase in knowledge and committed to applying the skills gained from the intervention during their interactions with patients.

Many HBCU students, student leaders, and staff members have not been educated about PrEP, which is an important tool for HIV and AIDS prevention. Morehouse is likely the first HBCU to begin offering PrEP to its students for the prevention of HIV and AIDS. Morehouse currently partners with Kaiser Permanente of Georgia, Gilead Sciences, the Fulton County Health Department, and other organizations to help make PrEP affordable.

Medicaid has not been expanded in many Southern U.S. states. This negatively impacts access to care, which in turn decreases the chances of early screening and treatment for HIV and AIDS, especially on HBCU campuses. Currently, a one-month supply of PrEP sells for over \$1500. Many Black Americans lack of insurance and the recent Trump Administration's rollbacks to Patient Protection and Affordable Care Act (ACA) provisions are likely to negatively impact HIV and AIDS care, especially among HBCU students, as out-of-pocket costs for PrEP formulations such as Truvada could easily exceed \$20,000 yearly without insurance coverage. An agreement in May 2019 between the Administration and Gilead Sciences will allow the pharmaceutical company to donate just over 2 million bottles of Truvada for PrEP annually to the CDC over the next 11 years. This arrangement will ensure that the formulation will be accessible to the uninsured and underinsured until the year 2030. HBCUs stand to benefit from this provision, as they have the highest HIV and AIDS rates as compared to other communities and populations within the U.S.



**POLICY RECOMMENDATIONS:** BWHI supports:

- Implementing public-private partnerships to educate young adults on HIV and AIDS prevention on their campuses;
- Raising awareness and increasing visibility of STIs on college campuses;
- Implementing a required introductory health course, which educates students about the basic information such as proper condom use and STI prevention facts;
- Incorporating HIV education as part of a required introductory health course;
- Increasing awareness of the benefits of testing and other HIV and AIDS prevention and care on HBCU campuses;
- Developing community-based strategies tailored to college-age students;
- Providing access to free or affordable HIV testing on campuses and counseling services for students living with HIV;
- Implementing or offering reproductive and sexual health education classes on HBCU campuses;
- Developing HIV policies that encompass prevention strategies, testing, and support services for students who have HIV;
- Developing HIV and AIDS awareness events as a way to raise visibility to college-age students;
- Establishing campus support groups for students living with HIV; and
- Organizing stakeholder roundtable meetings with HBCU presidents and senior leadership to facilitate campus conversations on strategies to end the HIV epidemic and the role HBCUs can play in that endeavor.



## REPRODUCTIVE HEALTH

Black WLHIV can take control of their reproductive health. WLHIV should have the same choices regarding whether or not to give birth as HIV-negative women and can, like their HIV-negative counterparts, give birth to healthy children.

Some HIV medications reduce the effectiveness of some hormonal birth control methods. Women taking HIV medication may need to use different or additional forms of birth control to prevent unplanned pregnancy.<sup>97</sup> The domestic gag rule's shuttering of reproductive health clinics also deeply impacts HIV-related care (such as access to preventive measures like condoms, testing, and connection to treatment) and may cause an increase in HIV transmission.

Approximately 6,000-7,000 WHLIV give birth annually.<sup>98</sup> Vertical, or perinatal, HIV transmission refers to HIV transmission from a WLHIV to her child during pregnancy, childbirth, or breastfeeding. Perinatal HIV transmission is the most common way children acquire HIV.<sup>99</sup>

Perinatal HIV transmission is not inevitable. Rather, the risk of transmission from mother to child is very low if:


- HIV is detected either before pregnancy or early in pregnancy;
- WLHIV receive specific treatment during pregnancy and childbirth to prevent transmission. When a pregnant WLHIV receives treatment, she increases the odds of reducing her viral load to levels that significantly lessen the risk of transmitting HIV to her child. Among WLHIV in the U.S. who do not receive HIV treatment, it is estimated that 25 percent of their children will be born with HIV. With treatment, the odds of transmission are estimated at less than 2 percent; and
- A baby born to a woman living with HIV receives HIV medications for 4-6 weeks after birth and is not breastfed.<sup>100</sup>

While perinatal HIV transmission declined by more than 40 percent during the period 2012-2016,<sup>101</sup> in 2017, there were 73 diagnoses of perinatal HIV in the U.S.<sup>102</sup> Of this number, Black women accounted for 64 percent of transmissions.<sup>103</sup>

**POLICY RECOMMENDATIONS:** BWHI supports fully integrating sexual and reproductive health services with HIV services so that the needs of WLHIV are met. We also support repealing policies that criminalize or stigmatize women for negative pregnancy outcome. (This is very relevant re: drug use, and this could be an important recommendation at the intersection of pregnancy, drug use, and HIV.) Public and private health insurance should cover the full range of sexual, reproductive, and family planning services for PLHIV regardless of gender identity, including pre- and postnatal care. BWHI opposes changes to Title X, Medicaid work requirements, and efforts to diminish coverage gains through the ACA.

# ACCESS TO CARE





More than 700,000 people have died of HIV-related causes since the first reported cases in 1981.<sup>104</sup> When HIV and AIDS first became widely known in the 1980s, they were regarded as a death sentence. However, the life expectancy of PLHIV has increased dramatically in recent years, largely due to antiretroviral medications that allow a person to treat HIV and AIDS as a chronic condition much like diabetes.

While a cure for HIV has yet to be found, regular antiretroviral treatment can reduce the presence of HIV in the blood to undetectable levels.<sup>105</sup> This results in improved health for PLHIV and virtually no risk of transmitting the virus to HIV-negative partners.

However, even with the increased availability of medications that have dramatically improved health outcomes, death is still a real concern for Black Americans living with HIV and AIDS. Notably, women are less likely to be virally suppressed than men.<sup>106</sup> In 2016, HIV was the fifth leading cause of death for Black women ages 35-44.<sup>107</sup>

Early detection and timely treatment are key to successfully managing HIV in a way that extends one's life expectancy and reduces the risk of transmission. As a consequence, access to comprehensive insurance coverage and programs that fill gaps in health coverage are critical to efforts to prevent new HIV transmission and achieve viral suppression in those who are living with HIV.



## HEALTH CARE REFORM

Passage of the ACA in 2010 led to improved and more affordable health coverage options for millions of Americans living with HIV. Key components of the law, as enacted, that impact PLHIV include:<sup>108</sup>

- **Prevention** – The ACA requires that covered plans pay for preventative services – without additional cost-sharing, such as co-pays and deductibles – that the USPSTF grants an “A” or “B” rating. HIV testing is covered under this mandate. Notably, USPSTF recently gave PrEP a Grade A recommendation, meaning that public and private insurers now will be obligated to cover the medication without cost-sharing by 2021.<sup>109</sup>
- **No Pre-Existing Conditions Exclusions** – Insurance companies cannot refuse coverage or charge more for coverage due to a pre-existing condition (a health issue that pre-dates new health coverage). In addition, once a person acquires a covered plan, the plan cannot refuse coverage for the pre-existing condition.
- **No Lifetime Limits** – Under the current law, lifetime limits on most benefits are prohibited in any health plan or insurance policy.
- **Coverage of Essential Health Benefits** – Most plans must cover essential health benefits which include services in the following categories: (1) ambulatory patient services; (2) emergency services; (3) hospitalization; (4) maternity and newborn care; (5) mental health and substance use disorder services, including behavioral health treatment; (6) prescription drugs; (7) rehabilitative and habilitative services and devices; (8) laboratory services; (9) preventive and wellness services and chronic disease management; and (10) pediatric services, including oral and vision care.
- **Medicaid Expansion** – Under the ACA, states have the option to expand Medicaid to provide cost-free health coverage to persons with incomes at or below 138 percent of the federal poverty level.
- **More Affordable Care** – The ACA provides financial assistance for people with low and middle incomes in the form of tax credits that lower the cost of monthly premiums and out-of-pocket expenses.
- **Nondiscrimination** – The law also prohibits discrimination based on race, color, national origin, sex, age, and disability in health programs and activities receiving federal financial assistance.

Since enactment of the ACA, Republicans in Congress, conservative state leaders and organizations, and the current President have repeatedly sought to repeal or undermine the law through legislation (both federal and state), federal regulation, and litigation.

**POLICY RECOMMENDATIONS:** BWHI supports preserving and improving upon the ACA to ensure Americans living with HIV retain access to affordable, quality, and comprehensive health care. BWHI opposes the development of insurance products allowed to be exempt from the ACA insurance requirements, rendering the coverage costly and meaningless. Furthermore, BWHI supports increasing investments in minority-serving health clinics to combat health disparities and ensure access to essential health care services.

## MEDICAID

Medicaid is the U.S. health care program for people living in poverty or low-income situations. The majority of Medicaid enrollees are women.<sup>110</sup> Further, 25 percent of Black women are enrolled in the Medicaid program.<sup>111</sup> Medicaid provides health coverage for more than 40 percent of PLHIV in the U.S.<sup>112</sup>

As initially written, the ACA required states to expand Medicaid to provide cost-free health coverage to persons with incomes at or below 138 percent of the Federal Poverty Level, including single adults without children who previously were not generally eligible for Medicaid. However, in 2012, the Supreme Court ruled that states were not required to expand Medicaid benefits.<sup>113</sup> As a result, millions who could be eligible to receive Medicaid under the ACA do not have access to this coverage. At present, 14 states have not yet opted to expand Medicaid eligibility.<sup>114</sup> As a consequence, almost 40 percent of PLHIV reside in states that have not yet expanded access to their Medicaid programs.<sup>115</sup> Notably, a number of the states that the Trump Administration plans to target with resources to address high rates of HIV have not expanded Medicaid enrollment.<sup>116</sup>

In addition to opposing Medicaid expansion, the Trump Administration has sought to impose additional burdens on persons who rely on Medicaid. In January 2018, Centers for Medicare and Medicaid Services (CMS) issued guidance that would, for the first time ever, allow states to place work requirements on current and future Medicaid enrollees. As a result, states could require Medicaid recipients to be employed and/or engage in community service as a condition for receiving health care benefits.<sup>117</sup> In Arkansas, imposition of the Medicaid work requirements led to nearly 17,000 people losing their health coverage.<sup>118</sup> In March 2019, a federal judge opposed implementation of Medicaid work requirements by Arkansas and Kentucky.<sup>119</sup> It remains to be seen whether any state plan for imposing work requirements on Medicaid recipients will withstand federal court scrutiny.

Furthermore, in its current 2020 budget proposal, the Trump Administration proposes cutting \$241 billion from Medicaid over the next decade as part of a plan that would result in states wielding more power over the program.<sup>120</sup> If implemented, such a plan is expected to result in 1.7 million individuals losing Medicaid coverage.<sup>121</sup>

**POLICY RECOMMENDATIONS:** BWHI supports and recommends increasing health care access for low-income Black women through the expansion of Medicaid in all 50 states and the protection of Medicaid as a safety net program with no harmful waivers such as work requirements, premiums, or time limits. BWHI opposes all efforts to further weaken the program. While the current Administration's stated commitment to providing additional federal resources to fight HIV and AIDS is welcome, such resources should not come at the expense of funding dedicated to programs, such as Medicaid, that already are providing needed medical services to persons living with HIV and AIDS.



## MEDICARE

Medicare is the federal health insurance program for persons age 65 years of age and older and for younger persons with permanent disabilities. Medicare is an important source of health coverage for PLHIV. The number of Medicare enrollees living with HIV nearly tripled between the 1990s and 2014.<sup>122</sup> Medicare represents the single largest source of federal funding for HIV care and treatment.<sup>123</sup> As HIV treatment improves, thereby extending the life spans of PLHIV, more persons are aging into Medicare.<sup>124</sup>

The Medicare Modernization Act created the Medicare Part D program. This program provides a prescription drug benefit to qualifying Medicare enrollees. Medicare Part D plans are required to cover all, or substantially all, of the drugs in each of six categories. Antiretroviral treatment for HIV infection is one of the “six protected classes” of drugs and must be covered without restriction. The majority of Medicare beneficiaries with HIV also are eligible for Medicaid.<sup>125</sup> In 2014, 77 percent of HIV-positive Medicare beneficiaries qualified for Medicare Part D subsidies.<sup>126</sup>

In early 2019, the Department of Health and Human Services (HHS) proposed modifying the six protected classes coverage requirements by allowing Medicare Part D plans to limit access to high-cost drugs, that did not provide Part D plans with rebates or negotiated fixed prices. The proposed rule would require (1) prior authorization for prescribing of high cost drugs, and (2) patients to first try a lower-cost drug, transitioning to higher costs drugs if the initial treatment fails.<sup>127</sup> HHS eventually issued a rule that maintains the six protected classes’ coverage requirements with no new exceptions or limitations.<sup>128</sup>

**POLICY RECOMMENDATIONS:** As the life expectancy of PLHIV continues to be extended, thanks in large part to advances in medical treatment and medicine, Medicare as a federal health care safety net becomes even more essential. Cost-cutting should never override quality of care. BWHI opposes any effort to eliminate or water down the critical drug coverage offered through the Medicare Part D program.

## RYAN WHITE HIV/AIDS PROGRAM (RWHAP)

In 1990, Congress passed the Ryan White Comprehensive AIDS Resources Emergency Act (Ryan White CARE Act) to address the impact of HIV in the U.S. The legislation has been amended and reauthorized four times in 1996, 2000, 2006, and 2009. Unlike Medicaid, the Ryan White HIV/AIDS Program (RWHAP) is a discretionary program to which federal budget resources are allocated each year. Once those resources are depleted in a given year, no new resources are available until the following year. Further, the program only covers costs of care when no other resource – public or private – is available. Funding for RWHAP has remained at about \$2.3 billion per year since 2010.<sup>129</sup>

RWHAP is regarded as significant in the provision of services for persons living with HIV and AIDS. Specifically:

- The program serves more than half of all persons living with HIV and AIDS in the U.S.<sup>130</sup>
- In 2016, approximately 47 percent of the program's recipients were Black.<sup>131</sup>
- The program, through Part B, provides funding for local AIDS Drug Assistance Programs (ADAPs) which offer HIV medication for low-income persons with little to no access to private or public insurance. In 2015, more than 250,000 people were enrolled in ADAPs. Viral suppression among Black RWHAP clients increased from 63.3 percent in 2010 to 82.6 percent in 2016.<sup>132</sup>

Notably, in 2018, the Trump Administration shifted funding from RWHAP, among other programs, to fund housing for undocumented immigrant children in U.S. custody.<sup>133</sup>

**POLICY RECOMMENDATIONS:** RWHAP has been critical to the provision of care to persons living with HIV and AIDS in the U.S. for nearly 30 years. Given the increase in the number of PLHIV and the ballooning cost of care, BWHI recommends that additional federal resources of at least \$50 million<sup>134</sup> be dedicated to strengthening and expanding the services offered by the program. In addition, BWHI objects to any diversion of resources from RWHAP and recommends integrating sexual and reproductive health services throughout the program.

## NONDISCRIMINATION PROTECTIONS

Section 1557 of the ACA makes it unlawful for any health care provider receiving federal funding to discriminate on the basis of race, color, national origin, sex, age, or disability. Under the HHS final regulation to Section 1557, sex discrimination is defined to include discrimination based on gender identity.<sup>135</sup> The final rule also provides that covered entities must take steps to provide meaningful access to persons with limited English proficiency (LEP).<sup>136</sup> The HHS Office for Civil Rights (OCR) is charged with enforcing Section 1557.

In June 2019, HHS issued a proposed rule to Section 1557 regulation that, among other things, eliminates the prohibition against discrimination based on gender identity. In addition, the proposed rule would eliminate the protections for persons with LEP.<sup>137</sup>

**POLICY RECOMMENDATIONS:** BWHI opposes removing Section 1557 protections against gender identity discrimination. This policy position comports with federal courts that have repeatedly concluded that federal sex discrimination laws also protect against discrimination based on gender identity.





## ONLINE PHARMACIES

Increasingly, there is the risk of substandard and counterfeit drugs – including ones identified as PrEP – being offered on the black market and by illegal online drug sellers. Leveraging patients' search for affordable, accessible treatments, an estimated 600 new illegal online pharmacy websites are launched each month. In total, there are more than 30,000 online pharmacies active at any given time with more than 95% operating in violation of state and federal law and relevant pharmacy practice standards. Drugs sold by illegal online pharmacy websites are often counterfeit and can contain too much, too little or altogether no active pharmaceutical ingredient. This is especially significant for persons at high risk for and living with HIV who may turn to the black market and online pharmacies to acquire cheaper and more readily accessible – albeit counterfeit or substandard – PrEP or antiretroviral products. Disease management and effective reduction in transmission is contingent upon administration of reliable, effective and authentic prescription drugs. Deviations from FDA-approved formulations could have significant – if not deadly – impacts for patients, especially Black WLHIV.

**POLICY RECOMMENDATIONS:** While BWHI encourages policies that improve access to PrEP and other antivirals for the treatment of HIV/AIDS, simultaneous efforts must be undertaken to ensure these products remain authentic, safe and effective. As a consequence, BWHI supports efforts calling for funding to be allocated to educate medical professionals (including patients and caregivers) on how to identify safe sources of medications online, including those products for the prevention or treatment of HIV/AIDS and related protocol.

## GLOBAL CONSIDERATIONS

The transmission and treatment of HIV is an issue global in scope. HIV and AIDS still are a leading cause of death worldwide. In 2018, 770,000 lost their lives to HIV and AIDS.<sup>138</sup> Moreover, in 2018:

- There were 37.9 million people worldwide living with HIV and AIDS (this includes 1.7 million children under the age of 15).
- There were 1.7 million new HIV transmissions (including 160,000 children).
- Every week, approximately 6,200 young women aged 15 to 24 contracted HIV.
- More than 8 million people did not know they were living with HIV.
- Among those who knew their HIV status, 78 percent were accessing treatment.
- Approximately 20 percent of PLHIV globally were unaware of their HIV status.<sup>139</sup>

The U.S. has expressed a commitment to working to prevent the transmission of HIV globally and aiding efforts to provide comprehensive treatment to PLHIV. The President's Emergency Plan for AIDS Relief (PEPFAR), launched in 2003, is a bipartisan initiative that supports prevention efforts and treatment for those living in countries hardest hit by HIV. PEPFAR represents the largest commitment by any nation in the world to address a single disease. Providing assistance to more than 50 countries, PEPFAR has been reauthorized three times – in 2003, 2013, and 2018.<sup>140</sup>

Through PEPFAR, the U.S. has supported prevention and treatment efforts that, among other things, have resulted in:

- HIV testing and counseling for 95 million people;
- Nearly 15 million people receiving HIV treatment;
- Antiretroviral treatment for more than 700,000 children;
- HIV treatment that prevented perinatal transmission to more than 2 million babies; and
- Approximately 270,000 trained health workers.<sup>141</sup>

While PEPFAR has proven to be effective, funding for the program has essentially been stagnant for years despite advances in treatment and the fact that PLHIV are living longer.<sup>142</sup> In FY 2019, the program was funded at 6.78 billion.<sup>143</sup> In addition, President Trump's 2020 budget recommendation has proposed a significant reduction in PEPFAR's funding.<sup>144</sup> His Administration also has advocated directing PEPFAR funding to fewer countries.<sup>145</sup>

**POLICY RECOMMENDATIONS:** BWHI opposes cutting funding from PEPFAR. In addition, BWHI recommends that the program be reauthorized to increase funding, taking into account the rising cost of drugs and the growing number of people needing additional supports because they are living longer with HIV and AIDS. In addition, BWHI recommends that PEPFAR's authorizing legislation and implementing regulations be amended to:

- Fund needle exchange programs;
- Ensure that PEPFAR funds are not directed to organizations that engage in anti-LGBTQ rhetoric;
- Encourage the repeal of laws that criminalize certain sexual activity;
- Encourage the advancement of more balanced strategies for HIV prevention that are not focused solely on abstinence;
- Strengthen accountability measures; and
- More actively support community-based organizations.<sup>146</sup>

# LIVING WITH HIV







In the early days of HIV and AIDS, death rates were high, and treatment options were few and largely ineffective.

Today, more than 470,000 of the 1.1 million Americans living with HIV are Black,<sup>147</sup> and many have lived with HIV for decades. As health outcomes dramatically improve, especially for those who achieve viral suppression, issues other than medical care are important to consider.

## HOUSING

The links between the effect of stable housing on better health outcomes is well documented. This is especially true when considering the most vulnerable communities, such as PLHIV.

Administered through the Department of Housing and Urban Development (HUD), the Housing Program for Persons with AIDS (HOPWA), established through the National Affordable Housing Act of 1990, is the only federal program dedicated to the housing needs of low-income persons living with HIV and AIDS and their families. Under HOPWA, HUD makes grants to states, local communities, and non-profit organizations for projects that benefit this population. The majority of the funds appropriated for the HOPWA program (90 percent) are distributed via formula grants. In 2016, this formula was updated to ensure that funds are targeted to areas hardest hit by HIV transmissions.

HOPWA funding has remained relatively flat over the last decade. In 2016, \$335 million was appropriated for the program. While this amount represented a \$5 million increase over 2015 funding, it equaled funding appropriated for HOPWA in 2010. Significantly, in 2015, 55,000 households received HOPWA funding, a decrease from previous years.

Homelessness remains at a high level; more than 550,000 Americans are homeless on any given day, and 1.42 million U.S. residents relied on an emergency shelter or transitional housing at some point in 2017.<sup>148</sup> Homeless PLHIV who are provided with rapid rehousing and intensive, tailored case management are placed in stable housing more quickly and are twice as likely to be virally suppressed when compared to individuals receiving standard homelessness support, according to research conducted in New York City and published in *AIDS and Behavior*.<sup>149</sup>

A survey of all available literature in eight health and social science databases from 1996 to 2014, *Housing Status and Health Outcomes*, synthesizes the results from 152 studies that examined housing status in relation to health-related outcomes for PLHIV in high-income countries.<sup>150</sup> Many of these studies share similar findings, allowing the report's authors to draw conclusions supported by multiple articles.<sup>151</sup>

Major findings:

- Homelessness for those living with HIV decreases adherence to antiretroviral plans, increases the risk of premature death, and negatively affects people's mental health and quality of life.<sup>152</sup>
- HIV-positive people with unstable housing are more likely than those with stable housing to need care from hospitals' emergency departments and inpatient care, suggesting weaknesses in chronic care management and unnecessarily high health care costs.<sup>153</sup>
- Stable housing decreases the prevalence of risky behaviors (among those with HIV) that can lead to the transmission of the disease.<sup>154</sup>

Finding the right housing for WLHIV can have its own set of challenges.<sup>155</sup> Many WLHIV do not earn enough money to afford a decent place to live because they are taking care of children, spouses, and other family members.<sup>156</sup> Women may find that they qualify for housing, while their loved ones – especially male partners and teenage sons – do not.<sup>157</sup>

It can be helpful to look beyond HIV-related housing for women and families.<sup>158</sup> There may be housing and shelter options available for battered women, for pregnant women, for women coming out of jail, and for women needing substance abuse treatment.<sup>159</sup> A woman should talk to her case manager or housing advocate about the people for whom she is caring and her housing needs in order to find the best program for her.<sup>160</sup>

**POLICY RECOMMENDATIONS:** BWHI recommends a substantial increase in funding for HOPWA. Stability in housing is important to achieving improved health outcomes for PLHIV. While many PLHIV are living longer, federal funding for housing has remained stagnant, resulting in a decrease in the number of persons helped by HOPWA. This is especially significant in light of the nationwide affordable housing crisis.



## EMPLOYMENT

With the help of current drug therapies, PLHIV can potentially enjoy long careers. It is difficult to determine to what extent living with HIV impact's one's ability to secure a job, because studies show that HIV hits hard on communities that already experience high rates of poverty and unemployment.<sup>161</sup> In addition, those PLHIV who do obtain employment must consider the impact of any employment on their continued eligibility for health coverage received from low-income health programs.<sup>162</sup>

**POLICY RECOMMENDATIONS:** BWHI recommends the development of federal and state programs that address the unique needs of PLHIV with respect to employment. Such a program would consider: (1) barriers to seeking and maintaining employment; (2) retirement options; (3) the impact of work on health; (4) achieving economic security, while not prematurely jeopardizing access to affordable health coverage; (5) inclusive paid sick, safe, and family leave; and (6) supporting “ban the box” hiring laws.



## HIV CRIMINALIZATION

HIV criminalization is the practice of utilizing state laws to prosecute and punish an individual based on their HIV status.<sup>163</sup> For decades, these laws have served to: refute medical fact and disregard advancement in treatments; deviate from generally accepted criminal law principles; conflict with public health policies; and they have stigmatized and discriminated against PLHIV.<sup>164</sup>

In the 1980's, when most of the state HIV-specific laws were promulgated, knowledge of the disease was in its infancy.<sup>165</sup> It was often considered a death sentence for those who contracted the virus.<sup>166</sup> Today, after years of research and advances in therapies, HIV is a manageable, chronic illness for those who have access to appropriate care and treatment.<sup>167</sup> Further, if the virus is detected early and the person has quality health care, then one can expect to live a near-normal life span.<sup>168</sup>

Despite the fact that the routes, risks, and likelihood of transmission are near zero when correct and when consistent condom use and effective antiretroviral therapy are in place, most state HIV-specific laws and prosecutions do not treat condom use, an undetectable viral load, or the extreme unlikelihood that transmission will occur, as evidence of a lack of intent to harm.<sup>169</sup> Also, contrary to scientific fact, saliva does not transmit HIV; yet, many states criminalize spitting and biting, with prison sentences as long as 35 years.<sup>170</sup>

In most jurisdictions, HIV-specific laws do not require proof of a person's intent to cause harm or to transmit HIV for a finding of guilt or a factor in determining the level of punishment.<sup>171</sup> Some HIV-specific laws also do not include actual HIV transmission as a specific element of the harm or conduct that is prohibited and punished.<sup>172</sup> In fact, HIV transmission is rarely a factor in HIV criminalization prosecutions.<sup>173</sup> In most states, even extremely low-risk or no-risk sexual activity, without disclosure, is subject to equally serious charges and sentences.<sup>174</sup>

Research demonstrates that HIV-specific laws do not reduce transmission, and a growing body of research shows that they may fuel the epidemic because they increase stigma, discourage testing, and make it more difficult for PLHIV to disclose their HIV status.<sup>175</sup> Placing legal responsibility for preventing disease transmission exclusively on people diagnosed with HIV undermines the most basic public health message concerning sexual health – that all people should practice behaviors that protect themselves and their partners from HIV and other sexually transmitted infections.<sup>176</sup> Perhaps more important, the laws do not appear to reduce rates of transmission. In fact, states that have harsher HIV criminal laws typically also have higher transmission rates.<sup>177</sup>

### Effects of HIV Criminalization on Women and Transgender Communities

HIV is a racial justice issue as well as a public health issue.<sup>178</sup> While it is common knowledge that PLHIV can be prosecuted under outdated criminal laws, what many do not realize is that racial bias may be adding another level of unfairness to the enforcement of these laws where people of color are concerned.<sup>179</sup> Consequences of being charged under an HIV criminalization law are severe – even without a conviction – and persist long after a person leaves the criminal justice system.<sup>180</sup> The long-term harm of experiencing HIV criminalization can impact every aspect of the person's life. In addition, six states require registration as a sex offender as part of the punishment under HIV-specific laws.<sup>181</sup> Further, for people of color living with HIV, racial discrimination diminishes the quality of medical care received.<sup>182</sup>

#### *The Effects on Women*

Studies have shown that HIV criminalization laws disproportionately target and harm women of color, particularly sex workers and women of trans experience.<sup>183</sup> In these cases, HIV criminalization laws can increase vulnerability to law enforcement and to intimate partners, who may threaten prosecution to coerce them into staying in an unhealthy or unsafe relationship.<sup>184</sup>

WLHIV are likely to have experienced intimate partner violence (IPV), sexual assault, physical and emotional abuse, and trauma at rates much higher than the general population in the U.S.<sup>185</sup> Specifically, the criminalization, policing, and incarceration of communities impacted by HIV are structural factors that contribute to high rates of IPV, sexual assault, and trauma among WLHIV.<sup>186</sup>



### ***The Effects on Black Women***

A majority of WLHIV in the U.S. are women of color and low-income women, who consequently live with the compounding effects of trauma resulting from HIV-related, gender, and racial discrimination, along with institutional violence entrenched in discriminatory practices and policies of public institutions such as the criminal justice system.<sup>187</sup>

It is well documented that the “War on Drugs” has resulted in mass criminalization, surveillance, and incarceration of communities of color. Drug laws are disproportionately used against women – especially Black women, who are more than twice as likely to be incarcerated than White women – and Latina women, who are 25 percent more likely to be incarcerated than White women.<sup>188</sup> Evidence suggests that mass incarceration also furthers the spread of HIV. According to some estimates, 14 percent (or 1 in 7) of all PLHIV in the U.S., and 20 percent (1 in 5) of Black Americans living with HIV will pass through a jail or prison every year.<sup>189</sup> Though there is variation from state to state, the prevalence of HIV in state and federal prisons in the U.S. is nearly five times greater than that of the general population.<sup>190</sup> The factors associated with disproportionate rates of incarceration – drug use, non-conforming sexual or gender identity, mental illness, poverty, sexual abuse, or just being a person of color – also increase a person’s risk of contracting HIV.<sup>191</sup>

### ***The Effects on Transgendered Individuals***

Transgender individuals are at the highest risk of HIV in the U.S.<sup>192</sup> According to the National Transgender Discrimination Survey, transgender women reportedly have over four times the national average of HIV infection, with rates much higher among transgender women of color.<sup>193</sup> In order for transgender individuals to feel comfortable disclosing HIV status, assuming it is known, it is important to create a system that does not stigmatize PLHIV. Multiple studies have shown that HIV criminalization increases discrimination and stigma, deters HIV testing, and does not serve as an effective method of HIV treatment and reduction.<sup>194</sup> The clear goal should be for lawmakers to prevent HIV, and this is not accomplished by enforcing HIV criminalization laws against individuals.<sup>195</sup>

According to the National HIV Criminalization Survey, 58 percent of transgender PLHIV believe it is reasonable to avoid HIV testing due to fear of HIV criminal prosecution and to general distrust of the criminal justice system.<sup>196</sup> “The data speak to the long-standing history of stigmatization and discrimination of trans people – especially trans people of color – by the criminal justice system, because of either their race or their gender identity.”<sup>197</sup>

## HIV Criminalization is a Matter of State Law

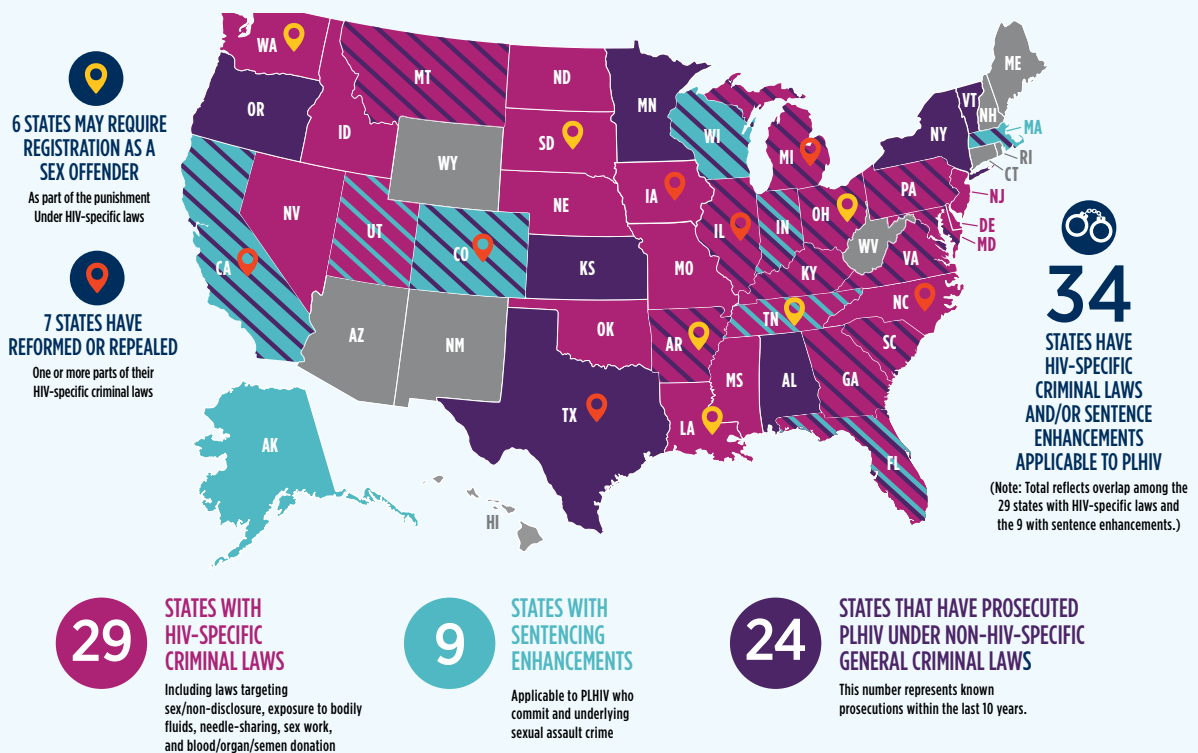
Criminalization of potential HIV exposure is largely a matter of state law, with some federal legislation addressing criminalization in discrete areas, such as blood donation and prostitution. These laws vary as to what behaviors are criminalized or result in additional penalties.<sup>198</sup> The maximum sentence length for violating an HIV-specific statute is also a matter of state law.<sup>199</sup> Some states have a maximum sentence length as high as life in prison, while others have maximum sentence lengths that are less than 10 years.<sup>200</sup> It should be noted that all states have general criminal laws – such as assault, battery, reckless endangerment, and attempted murder – that have been used to prosecute PLHIV for any of the above-mentioned behaviors.<sup>201</sup>

A number of states enacted laws that criminalized (or provided heavier penalties on) HIV/STI exposure by a person who knows they are living with HIV. At the end of 2018, 26 states had laws that criminalize HIV exposure. The state laws fall into at least one of five categories:

- HIV-specific laws that criminalize behaviors that potentially expose another to HIV.
- STI/communicable/infectious disease criminal laws that criminalize behavior that can potentially expose another to a STI/communicable/infectious disease. This could include HIV.
- Sentence enhancement specific to HIV. In this case, the behavior is not criminalized, but the punishment is enhanced when a person commits certain crimes while HIV positive.
- Sentence enhancements specific to STI/communicable/infectious disease.
- As with HIV sentence enhancements, committing certain crimes while having a STI/communicable/infectious disease can lead to heightened penalties.

## HIV CRIMINALIZATION IN THE UNITED STATES

An overview of the variety and prevalence of laws used to prosecute and punish people living with HIV (PLHIV) in the U.S.



SOURCE: <https://www.hivlawandpolicy.org/sites/default/files/CHLP%20HIV%20Crim%20Map%20030119.pdf>

Updated: March 1, 2019. Laws change frequently and this map is only accurate to the best of our knowledge. It is not a substitute for legal advice.





### ***California - An Example of a Legislative Transformation with HIV-Specific Laws***

While there is no state with an untarnished record and no history of prosecuting PLHIV, California is a shining example of legislators recognizing the inequities of HIV criminalization and instituting legislation to try to correct the broken system.

Women and people of color bear the heaviest burden of HIV criminal laws in California. The Williams Institute reports are the first to analyze California Criminal Offender Record Information (CORI) data on the criminal history of all individuals who have had contact with the criminal justice system under the state's four HIV-specific criminal laws.<sup>202</sup> Moreover, the report shows that Black and Latinx people made up 67 percent of those who encountered the California criminal justice system related to HIV laws but made up only 51 percent of PLHIV in the state.<sup>203</sup>

Evidence also indicates that penalties associated with HIV-specific statutes are unevenly imposed on the basis of race and sex.<sup>204</sup> In California, for example, Black and Latino people compose half the population of people with HIV but two-thirds of defendants in HIV-criminalization cases; Black women, in particular, account for only four percent of the state's HIV-positive population but 21 percent of these cases.<sup>205</sup> Moreover, among people arrested for HIV-related crimes, White men were released and not charged in 61 percent of incidents, as compared with 44 percent of incidents for Black women, 39 percent for White women, and 38 percent for Black men.<sup>206</sup> Discriminatory enforcement of HIV-criminalization statutes compounds injustices based on race, sex, and socioeconomic status, and it undermines the retributivist rationale for HIV criminalization.<sup>207</sup>

Unlike most state legislation penalizing HIV exposure, California's new misdemeanor statute reflects up-to-date science.<sup>208</sup> The law applies only to people who know they have an infectious disease, who act with specific intent to transmit the disease to another person, who engage in conduct posing a substantial risk of transmission without attempting to prevent transmission, and who transmit the disease to someone who doesn't know that the person is infected.<sup>209</sup> Behaviors such as spitting and biting are not considered to pose substantial risk, and acquiring an infection while pregnant and refusing treatment while pregnant are specifically exempted.<sup>210</sup> The statute encompasses all infectious diseases, not just HIV – which may mitigate HIV-related stigma.<sup>211</sup>

California is not alone in taking a more evidence-based and less stigmatizing approach to HIV prevention.<sup>212</sup> In 2016, for example, Colorado repealed two HIV-criminalization laws and modernized its statutory language regarding sexually transmitted infections.<sup>213</sup> But, additional developments counsel against optimism; the Ohio Supreme Court recently upheld a charge of felonious assault for people with HIV who have sex without disclosing their HIV status.<sup>214</sup> Therefore, decriminalization is vital to our efforts to end these unjust prosecutions.

**POLICY RECOMMENDATIONS:** BWHI recommends:

- Passage of Pretrial Integrity and Safety Act introduced by U.S. Senators Kamala Harris (D-CA) and Carlos Curbelo (R-FL). This act would provide grants to states to assist in eliminating the use of money bail as a requirement of pre-trial release in criminal cases. This practice unjustly punishes low-income individuals, as it prolongs separation from family, community, work, school and other life responsibilities. For PLHIV, pretrial detainment may cause a disruption in critical care and treatment.<sup>215</sup>
- Passage of the REPEAL (Repeal Existing Policies that Encourage and Allow Legal) HIV Discrimination introduced by U.S. Rep. Barbara Lee. This act calls for the review of all federal and state laws and regulations regarding “the criminal prosecution of individuals for HIV-related offenses”. This bill expresses the sense of Congress that federal and state laws, policies, and regulations regarding PLHIV should: (1) not place unique or additional burdens on such individuals solely as a result of their HIV status; and (2) demonstrate a public health-oriented, evidence-based, medically accurate, and contemporary understanding of HIV transmission, health implications, treatment, and the impact of punitive HIV-specific laws, policies, regulations, and judicial precedents and decisions on public health and on affected people, families, and communities.
- Repeal of state HIV criminalization laws that create disproportionate penalties for disclosure, exposure or transmission of HIV disease beyond normal public health ordinances.
- Passage of the Community Safety and Health Amendment Act of 2019 introduced by Washington D.C. City Council and believes Black women should have agency over their own lives. This bill would seek the decriminalization of sex work in Washington, D.C. The criminalization of sex work denies such agency and autonomy and also disproportionately affects Black women. Criminalization and stigma related to sex work creates barriers to health care. We believe that all Black women and girls should have access to health care regardless of their work profession and that this access should be free of stigma.



## IMMIGRATION

HIV has influenced U.S. immigration policy and been used as a political weapon against immigrants for nearly 40 years. Unfortunately, throughout this period the fears about HIV and immigrants have not dissipated.

Gross inequities in the U.S. immigration system disproportionately harm HIV-affected people, documented or otherwise, and their families.<sup>216</sup> The legal, cultural, public health, and socioeconomic barriers created by the broken immigration system create substantial obstacles for PLHIV and their advocates.<sup>217</sup> The isolation and lack of health care available to immigrant populations impede HIV testing, treatment, and prevention efforts.<sup>218</sup>

Throughout the 20th Century, immigration laws relating to health have expanded and changed, with the purpose remaining the same: to keep medically compromised people, or those otherwise “undesirable” for health-related reasons, from entering the U.S.<sup>219</sup> Individuals who wish to obtain lawful immigration status in the U.S. must establish that they are not “inadmissible”, or not barred under U.S. law. The Immigration and Nationality Act (INA) lists the grounds of inadmissibility, which prior to 1996 were known as grounds of “exclusion”. One of the grounds for deniability is health-related problems. Specific health-related problems, including infection with HIV, automatically render a non-citizen inadmissible.<sup>220</sup> This law is sometimes referred to as “the HIV ban”.<sup>221</sup> Effective January 4, 2010, HIV is no longer a bar to entry into the U.S. for visitation or immigration purposes.<sup>222</sup> This means that HIV status alone cannot be a reason for excluding, removing, or deporting a person from the U.S.<sup>223</sup>





### Immigrating with HIV Today

Although HIV cannot be an exclusionary factor, there still remains the following obstacles and challenges:

- PLHIV who attempt to come to the U.S. face many more obstacles than those who are HIV negative.<sup>224</sup> The daunting challenge of navigating the U.S. immigration system and its voluminous paperwork rises to a new level of complexity and delay when living with HIV.<sup>225</sup> Someone in this situation confronts discrimination both for being a non-citizen of the U.S. and for having HIV.<sup>226</sup>
- HIV-related restrictions for those visiting or immigrating to a country exacerbate these problems by breaking families apart, dividing spouses, separating parents from their children, limiting employment and educational opportunities for PLHIV, and discouraging individuals from seeking testing or treatment for fear of being denied entry or placed on deportation proceedings.<sup>227</sup>
- PLHIV who are detained in immigration detention facilities, including those applying for asylum protection, often experience difficulty in accessing essential health care and drug therapies while in custody.<sup>228</sup>
- All immigrants also face legal barriers to accessing health insurance.<sup>229</sup> For five years after their arrival in the U.S., they cannot enroll in Medicaid or the Children's Health Insurance Program (CHIP), even if their immigration status is documented.<sup>230</sup> The ACA specifically excludes anyone who is undocumented from signing up for subsidized health insurance.<sup>231</sup>
- HIV criminalization laws either criminalize otherwise legal behavior or increase penalties for illegal conduct based on a person's HIV status. For immigrants, HIV criminalization laws can be even more detrimental, because being convicted of a crime can be grounds for deportation.<sup>232</sup>
- Hospitals and clinics can be confusing to navigate for non-English-speaking immigrants who are allowed care.

Black immigrants come to the U.S. from countries that include Jamaica, Haiti, and Nigeria face unique challenges, which exacerbate many of these aforementioned challenges.<sup>233</sup> In particular, they are impacted by stricter scrutiny when it comes to their HIV-status:

- African and Caribbean immigrants are disproportionately affected by HIV in the U.S., especially due to the lack of health insurance, low socioeconomic status, and cultural belief systems that sometimes keep people from seeking health care<sup>234</sup>
- African immigrants are more likely than people born in the U.S. to be diagnosed with AIDS within a year of HIV diagnosis.<sup>235</sup> Not only do late diagnoses lead to a higher mortality rate, but they also lead to an increased risk of HIV transmission.<sup>236</sup>

Moreover, the lack of research and data on the experiences of HIV-infected Black immigrants creates a disadvantage for health equity.<sup>237</sup> Unfortunately, statistics often categorize people by race and ethnicity, lumping together American and Black immigrants in one category.<sup>238</sup> Without accurate information about the scope of the problems that immigrants face, it is difficult to work toward effective solutions.<sup>239</sup>

A study conducted in part by the African Services Commission (ASC) found that approximately 25 percent of African immigrants acquired HIV after they arrived in the U.S.<sup>240</sup> These results suggest that there is a need for more culturally and linguistically appropriate prevention strategies.<sup>241</sup> Some immigrants may not speak English, making it critical to have people who can communicate with them.<sup>242</sup> Likewise, some immigrants might not be moved by prevention campaigns that are effective with people who were born in the U.S.<sup>243</sup> Care must be taken to make sure that the messaging of prevention and treatment campaigns appeals to those it is designed to reach.<sup>244</sup> Because African immigrants are more likely to be diagnosed at a later stage, it is also important to look at the diagnosis and provision of health care.<sup>245</sup> The lack of access that many Black immigrants have to health care services must also be addressed.<sup>246</sup>



### ***The Effects on Women Immigrants***

Immigrant WLHIV often juggle multiple identities, all of which are the target of discrimination and stigma: HIV status; female gender; person of color; foreign accent; and/or poor command of English.<sup>247</sup> Many immigrant women also come from countries with a high prevalence of HIV and/or have experienced trauma and abuse during their journey to the U.S.<sup>248</sup> These disadvantages are compounded by policies that prevent immigrants' access to health insurance, fear of immigration enforcement, low socioeconomic status, and cultural belief systems that may be at odds with mainstream norms.<sup>249</sup>

Women who immigrate to the U.S. from Africa face a different set of challenges from African-American women.<sup>250</sup> For one thing, many of the immigrant women come from countries with high HIV prevalence rates, speak limited English, and may be afraid of deportation if they access any services – including HIV testing and care.<sup>251</sup> The women also may have suffered female genital mutilation or the trauma of war and displacement.<sup>252</sup> To overcome such obstacles, ASC not only operates an HIV clinic but also provides escorts for appointments with government institutions, legal help for immigration questions, ESL classes, housing assistance, and other services.<sup>253</sup>

### ***The Effects on LGBTQ Immigrants***

More than a dozen human rights organizations have filed a formal complaint against the treatment of LGBTQ people and PLHIV in immigration detention facilities.<sup>254</sup> In a scathing rebuke to policies enacted by Immigration and Customs Enforcement (ICE) and Customs and Border Protection (CBP), states that “egregiously inadequate medical and mental health care” have jeopardized the “health, safety, and lives of individuals in federal custody,” and that the agencies’ neglect is in “clear violation of the U.S. Constitution, statutory law, and applicable detention standards”.<sup>255</sup>

The complaint calls attention to the “widespread abuse and mistreatment of LGBTQ, PLHIV individuals in ICE custody” and lists a series of demands, to address the agencies’ “continuing failure” in the treatment of such individuals.<sup>256</sup> “First and foremost,” the group requests the release of “all LGBTQ, PLHIV people who are currently detained on their own recognizance”.<sup>257</sup> Other demands include guarantees that people will not be held in CBP facilities longer than 24 hours, that licensed health professionals need to be competent in transgender and HIV-related care, and that all individuals in custody should receive timely medical screenings.<sup>258</sup>







### ***Impact of the Policies of the Trump Administration***

While being HIV-positive is no longer a ground for inadmissibility into the U.S., many immigrants have cause to be worried, due to the statements of Brian Hastings, CBP Chief of Law Enforcement,<sup>259</sup> at a House Judiciary Committee hearing, he stated that his agency considered HIV to be a communicable disease under a form of guidance used by agents to determine whether to separate children entries from parents.<sup>260</sup> Hastings further clarified that CBP would not separate families due to the communicable nature of HIV, but separation could be a consideration due to the potential requirement for hospitalization and whether it was in the best interest of the child to wait for the disposition of their parent in HHS or CBP custody.<sup>261</sup>

Immigrants seeking HIV care in the U.S. have to decide between one's own health and the safety of those one loves.<sup>262</sup> Do they venture out to their local clinic for the HIV medication they so desperately need – knowing that doing so could lead ICE not just to their doorstep, but to those of their friends and family – or do they remove themselves from care and stay in hiding, putting themselves in grave danger in an attempt to avoid deportation? It is an impossible question with no satisfactory answer.<sup>263</sup> In California, one survey found that 40 percent of the state's health care providers reported immigrant families canceling appointments or scheduling fewer visits, while a study of a health care provider network in Colorado showed a staggering 75 percent of providers reporting increases in appointment no-shows and cancellations by immigrant clients.<sup>264</sup> National-level inquiries have returned similar results, such a survey by the Migrant Clinicians Network showing roughly two in three health care providers polled reporting that their clients attitudes and feelings around health care had changed primarily due to the shift in immigration policies and fear resulting from those policies.<sup>265</sup>

A proposed change to a Department of Homeland Security (DHS) rule, known colloquially as the “public charge” rule, would essentially penalize lawfully residing immigrants for receiving any sort of public assistance, such as Medicaid or food stamps, by making it more difficult for them to become U.S. citizens.<sup>266</sup> If instituted, the public charge rule change would serve as a de facto ban on PLHIV immigrating to the U.S.<sup>267</sup> Among other things, the rule would require PLHIV to show proof of unsubsidized health insurance, effectively eliminating anyone utilizing Medicaid, the AIDS Drug Assistance Program, or any ACA cost-sharing subsidies from consideration for citizenship.<sup>268</sup>

In the midst of the increased detentions at the U.S. border, there is mounting evidence that people with HIV were not being given access to antiretroviral therapy, and several have died in custody.<sup>269</sup> For example, at least 17 known HIV-positive asylum seekers have died in ICE custody since 2003 when ICE was established.<sup>270</sup>

**POLICY RECOMMENDATION:** BWHI advocates for legislation which assists PLHIV to overcome immigration obstacles and the hurdles those communities face in procuring treatment, HIV testing, and prevention efforts.

## AWARENESS DAYS



December 1

**World AIDS Day**  
#WAD2019



February 7

**National Black HIV/AIDS Awareness Day**  
#NBHAAD



March 10

**National Women and Girls HIV/AIDS Awareness Day**  
#NWGHAAD



March 20

**National Native HIV/AIDS Awareness Day**  
#NNHAAD



April 10

**National Youth HIV & AIDS Awareness Day**  
#NYHAAD



April 18

**National Transgender HIV Testing Day**  
#TransHIV



May 18

**HIV Vaccine Awareness Day**  
#HVAD



May 19

**National Asian & Pacific Islander HIV/AIDS Awareness Day**  
#APIMay19



June 5

**HIV Long-Term Survivors Day**  
#empowered2thrive



June 27

**National HIV Testing Day**  
#HIVTestingDay



September 18

**National HIV/AIDS and Aging Awareness Day**  
#HIVandAging



September 27

**National Gay Men's HIV/AIDS Awareness Day**  
#NGMHAAD



October 15

**National Latinx AIDS Awareness Day**  
#NLAAD

**For more information visit:**  
<https://www.hiv.gov/events/awareness-days>



This is an official U.S. Government website managed by the U.S. Department of Health & Human Services and supported by the Minority HIV/AIDS Fund.

## GLOSSARY OF TERMS

**Ally** | A person who is not LGBTQ but shows support for LGBTQ people and promotes equality in a variety of ways.

**Androgynous** | Identifying and/or presenting as neither distinguishably masculine nor feminine.

**Asexual** | Lacking a sexual attraction or desire for other people.

**Biphobia** | Prejudice, fear or hatred directed toward bisexual people.

**Bisexual** | A person emotionally, romantically or sexually attracted to more than one sex, gender or gender identity though not necessarily simultaneously, in the same way or to the same degree.

**Cisgender** | A term used to describe a person whose gender identity aligns with those typically associated with the sex assigned to them at birth.

**Closeted** | Describes an LGBTQ person who has not disclosed their sexual orientation or gender identity.

**Coming out** | The process in which a person first acknowledges, accepts, and appreciates their sexual orientation or gender identity and begins to share that with others.

**Gay** | A person who is emotionally, romantically, or sexually attracted to members of the same gender.

**Gender dysphoria** | Clinically significant distress caused when a person's assigned birth gender is not the same as the one with which they identify. According to the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM), the term - which replaces Gender Identity Disorder - "is intended to better characterize the experiences of affected children, adolescents, and adults."

**Gender-expansive** | Conveys a wider, more flexible range of gender identity and/or expression than typically associated with the binary gender system.

**Gender expression** | External appearance of one's gender identity, usually expressed through behavior, clothing, haircut or voice, and which may or may not conform to socially defined behaviors and characteristics typically associated with being either masculine or feminine.

**Gender-fluid** | According to the Oxford English Dictionary, a person who does not identify with a single fixed gender; of or relating to a person having or expressing a fluid or unfixed gender identity.

**Gender identity** | One's innermost concept of self as male, female, a blend of both, or neither - how individuals perceive themselves and what they call themselves. One's gender identity can be the same or different from their sex assigned at birth.

**Gender non-conforming** | A broad term referring to people who do not behave in a way that conforms to the traditional expectations of their gender, or whose gender expression does not fit neatly into a category.

**Genderqueer** | Genderqueer people typically reject notions of static categories of gender and embrace a fluidity of gender identity and often, though not always, sexual orientation. People who identify as "genderqueer" may see themselves as being both male and female, neither male nor female, or as falling completely outside these categories.

**Gender transition** | The process by which some people strive to more closely align their internal knowledge of gender with its outward appearance. Some people socially transition, whereby they might begin dressing, using names and pronouns, and/or be socially recognized as another gender. Others undergo physical transitions in which they modify their bodies through medical interventions.

**Homophobia** | The fear and hatred of, or discomfort with, people who are attracted to members of the same sex.

**Intersex** | An umbrella term used to describe a wide range of natural bodily variations. In some cases, these traits are visible at birth, and in others, they are not apparent until puberty. Some chromosomal variations of this type may not be physically apparent at all.

**Lesbian** | A woman who is emotionally, romantically, or sexually attracted to other women.

**LGBTQ** | An acronym for "lesbian, gay, bisexual, transgender, and queer."

**Living openly** | A state in which LGBTQ people are comfortably out about their sexual orientation or gender identity - where and when it feels appropriate to them.

**Non-binary** | An adjective describing a person who does not identify exclusively as a man or a woman. Non-binary people may identify as being both a man and a woman, somewhere in between, or as falling completely outside these categories. While many also identify as transgender, not all non-binary people do.

**Outing** | Exposing someone's lesbian, gay, bisexual, or transgender identity to others without their permission. Outing someone can have serious repercussions on employment, economic stability, personal safety, or religious or family situations.

**Pansexual** | Describes someone who has the potential for emotional, romantic, or sexual attraction to people of any gender though not necessarily simultaneously, in the same way, or to the same degree.

**Queer** | A term people often use to express fluid identities and orientations. Often used interchangeably with "LGBTQ."

**Questioning** | A term used to describe people who are in the process of exploring their sexual orientation or gender identity.

**Same-gender loving** | A term some prefer to use instead of lesbian, gay, or bisexual to express attraction to and love of people of the same gender.

**Sex assigned at birth** | The sex (male or female) given to a child at birth, most often based on the child's external anatomy. This is also referred to as "assigned sex at birth".

**Sexual orientation** | An inherent or immutable enduring emotional, romantic, or sexual attraction to other people.

**Transgender** | An umbrella term for people whose gender identity and/or expression is different from cultural expectations based on the sex they were assigned at birth. Being transgender does not imply any specific sexual orientation. Therefore, transgender people may identify as straight, gay, lesbian, bisexual, etc.

**Transphobia** | The fear and hatred of, or discomfort with, transgender people.



## ENDNOTES

- 1 Centers for Disease Control (CDC), CDC factsheet – HIV among African Americans. Retrieved from <https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/cdc-hiv-aa-508.pdf>.
- 2 *ibid.*
- 3 CDC, Diagnosis of HIV infection in the United States and dependent areas, 2017. (2018, November). Retrieved from <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2017-vol-29.pdf>.
- 4 Kaiser Family Foundation (KFF). (2019, February 7). Black Americans and HIV/AIDS: The basics. Retrieved from <https://www.kff.org/hiv/aids/fact-sheet/black-americans-and-hiv-aids-the-basics/>.
- 5 Planned Parenthood, HIV & AIDS. Retrieved from <https://www.plannedparenthood.org/learn/stds-hiv-safer-sex/hiv-aids>.
- 6 *ibid.*
- 7 *ibid.*
- 8 Department of Veterans Affairs. HIV: Frequently Asked Questions. Retrieved from <https://www.hiv.va.gov/patient/faqs/once-a-day-pill.asp>.
- 9 Curran, James W. (2011, October 7). AIDS: The early years and CDC's Response. Retrieved from <https://www.cdc.gov/mmwr/preview/mmwrhtml/su6004a11.htm>.
- 10 Kirzinger, Ashley. (2019, March 20). Health tracking poll- March 2019: Public opinion on the domestic HIV epidemic, Affordable Care Act and Medicare-for-all. Retrieved from <https://www.kff.org/health-reform/poll-finding/kff-health-tracking-poll-march-2019/>.
- 11 U.S. Department of Health and Human Services (HHS). HIV basics: U.S. statistics. Retrieved from <https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>.
- 12 KFF. (2019, February 7). Black Americans and HIV/AIDS: The basics. Retrieved from <https://www.kff.org/hiv/aids/fact-sheet/black-americans-and-hiv-aids-the-basics/>.
- 13 HHS. HIV basics: U.S. statistics. Retrieved from <https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>.
- 14 *ibid.*
- 15 *ibid.*
- 16 *ibid.*
- 17 KFF. (2019, February 7). Black Americans and HIV/AIDS: The basics. Retrieved from <https://www.kff.org/hiv/aids/fact-sheet/black-americans-and-hiv-aids-the-basics/>.
- 18 Wolitski, Richard. (2018, February 7). HIV in the African American community: Progress, but our work is far from over. Retrieved from <https://www.hiv.gov/blog/hiv-african-american-community-progress-our-work-far-over>.
- 19 CDC. HIV among African Americans. Retrieved from <https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/cdc-hiv-aa-508.pdf>.
- 20 CDC. (2019, April). HIV and transgender people. Retrieved from <https://www.cdc.gov/hiv/group/gender/transgender/index.html>.
- 21 *ibid.*
- 22 Georgia Department of Public Health (2016) HIV/AIDS Epidemiology Section HIV Surveillance Summary, Georgia 2014. Available at: <https://dph.georgia.gov/data-fact-sheet-summaries>
- 23 Amfar, Statistics (2019) Women and HIV/AIDS. Available at: <https://www.amfar.org/about-hiv-and-aids/facts-and-stats/statistics--women-and-hiv-aids/>
- 24 TCCGroup (2017) Network that Care: An Ethnographic Research Study of Black Women in New Orleans [https://www.tccgrp.com/wp-content/uploads/Networks-of-Care\\_forwebsite\\_reducedfilesize.pdf](https://www.tccgrp.com/wp-content/uploads/Networks-of-Care_forwebsite_reducedfilesize.pdf). (citing The National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Atlas. Centers for Disease Control and Prevention. Available at: <http://www.cdc.gov/nchhstp/atlas/>.)
- 25 AIDSvu (2017) Local Data: Atlanta. Available at: <https://aidsvu.org/local-data/united-states/south/georgia/atlanta/>
- 26 *ibid.*
- 27 TCCGroup, *supra* note 3 (citing Centers for Disease Control and Prevention. HIV Surveillance Supplemental Report - Diagnosed HIV Infection among Adults and Adolescents in Metropolitan Statistical Areas—United States and Puerto Rico, 2014. Vol 21(1), table 7b, p. 58. 2016. Available at: <http://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-21-1.pdf>.)
- 28 SisterLove, Inc (2017) Intersections at the Grassroots: A Reproductive Justice Analysis of Atlanta's HIV Epidemic
- 29 TCCGroup, *supra* note 2 (citing AIDSvu.org. <http://aidsvu.org/state/louisiana/new-orleans/>)
- 30 AIDSvu, *supra* note 4.
- 31 SisterLove, Inc, *supra* note 4.
- 32 *ibid.*
- 33 TCCGroup, *supra* note 3 (citing the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Atlas. Centers for Disease Control and Prevention. <http://www.cdc.gov/nchhstp/atlas/>)
- 34 *ibid.*
- 35 *ibid.*
- 36 *ibid.*
- 37 Garfield, R. (2016) The Coverage Gap: Uninsured Poor Adults In States That Do Not Expand Medicaid. Available at: <http://kff.org/uninsured/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/>
- 38 Reed, K. (2016) City Council Votes To Allow Negotiations To Proceed Over Atlanta Shelter. Available at: <http://www.11alive.com/news/local/peachtree-pine-homeless-shelter/328580107>.
- 39 TCCGroup, *supra* note 2
- 40 TCCGroup, *supra* note 2.
- 41 SisterLove, Inc, *supra* note 4.
- 42 SisterLove, Inc, *supra* note 4.
- 43 CDC. (2019, September 27). Facts about HIV stigma. Retrieved from <https://www.cdc.gov/hiv/basics/hiv-stigma/index.html>.
- 44 *ibid.*
- 45 *ibid.*
- 46 *ibid.*
- 47 This is especially significant in the criminal justice context, as discussed later in this document.
- 48 Stigma. Retrieved from <https://www.hivlawandpolicy.org/issues/stigma>.
- 49 Joint United Nations Programme on HIV/AIDS (UNAIDS). (2017, October 2). Confronting discrimination: Overcoming HIV-related stigma and discrimination in health care settings and beyond. Retrieved from <https://www.unaids.org/en/resources/documents/2017/confronting-discrimination>.
- 50 *ibid.*
- 51 *ibid.*
- 52 *ibid.*
- 53 CDC. (2019, June 27). Most Americans have never taken an HIV test new data show. Retrieved from <https://www.cdc.gov/media/releases/2019/p0627-americans-hiv-test.html>.
- 54 *ibid.*
- 55 *ibid.*
- 56 *ibid.*
- 57 *ibid.*
- 58 HHS. HIV basics: U.S. statistics. Retrieved from <https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>.
- 59 *ibid.*
- 60 CDC. (2019, November 8). HIV Testing. Retrieved from <https://www.cdc.gov/hiv/testing/index.html>.
- 61 National Institutes of Health (NIH). (2019, January 10). The science is clear: with HIV, undetectable equals untransmittable. Retrieved from <https://www.nih.gov/news-events/news-releases/science-clear-hiv-undetectable-equals-untransmittable>.
- 62 CDC. (2019, October 17). PrEP. Retrieved from <https://www.cdc.gov/hiv/basics/prep.html>.
- 63 U.S. Food and Drug Administration (FDA). (2019, October 3). FDA approves second drug to prevent HIV infection as part of ongoing efforts to end the HIV epidemic. Retrieved from <https://www.fda.gov/news-events/press-announcements/fda-approves-second-drug-prevent-hiv-infection-part-ongoing-efforts-end-hiv-epidemic>.
- 64 *ibid.*
- 65 Goldstein, Robert. (2019, October 4). PrEP prevents HIV – so why aren't more people taking it?. Retrieved from <https://www.health.harvard.edu/blog/prep-prevents-hiv-so-why-arent-more-people-taking-it-2019100417942>.
- 66 Huang, Ya-Lin A. (2018, October 19). HIV preexposure prophylaxis, by race and ethnicity – United States, 2014–2016. Retrieved from <https://www.cdc.gov/mmwr/volumes/67/wr/mm6741a3.htm>.

- 67 Weatherspoon, Lynsey. (2019, February 8). To halt HIV, advocates push for PrEP outreach to black women. Retrieved from <https://www.npr.org/sections/health-shots/2019/02/08/691740052/to-halt-hiv-advocates-push-for-prep-outreach-to-black-women>.
- 68 HHS. (2019, June 26). Pre-exposure prophylaxis. Retrieved from <https://www.hiv.gov/hiv-basics/hiv-prevention/using-hiv-medication-to-reduce-risk/pre-exposure-prophylaxis>.
- 69 CDC. (2015, November 24). Daily pill can prevent HIV. Retrieved from <https://www.cdc.gov/vitalsigns/hivprep/index.html>.
- 70 Weatherspoon, Lynsey. (2019, February 8). To halt HIV, advocates push for PrEP outreach to black women. Retrieved from <https://www.npr.org/sections/health-shots/2019/02/08/691740052/to-halt-hiv-advocates-push-for-prep-outreach-to-black-women>.
- 71 *ibid.*
- 72 U.S. Preventive Services Task Force. (2019, June 11). Final recommendation statement: Screening for HIV infection. Retrieved from <https://www.uspreventiveservicestaskforce.org/Announcements/News/Item/final-recommendation-statement-screening-for-hiv-infection>.
- 73 Harris, Kamala. S. (2019, June 20). 1926: PrEP Access and Coverage Act. Retrieved from <https://www.govtrack.us/congress/bills/116/s1926/text>.
- 74 CDC. (2019, August). Injection drug use and HIV risk. Retrieved from <https://www.cdc.gov/hiv/pdf/risk/cdc-hiv-idu-fact-sheet.pdf>.
- 75 *ibid.*
- 76 CDC. (2019, May 23). Syringe Services Programs (SSPs). Retrieved from <https://www.cdc.gov/ssp/>.
- 77 *ibid.*
- 78 KFF. Sterile Syringe Exchange Programs. Retrieved from <https://www.kff.org/hiv/aids/state-indicator/syringe-exchange-programs/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>.
- 79 CDC. Program guidance for implementing certain components of syringe services programs, 2016. Retrieved from <https://www.cdc.gov/hiv/pdf/risk/cdc-hiv-syringe-exchange-services.pdf>.
- 80 *ibid.*
- 81 The Foundation for AIDS Research (amfAR). (2013, March). Public safety, law enforcement and syringe exchange. Retrieved from [https://www.amfar.org/uploadedFiles/amfarorg/Articles/On\\_The\\_Hill/2013/fact%20sheet%20Syringe%20Exchange%20031913.pdf](https://www.amfar.org/uploadedFiles/amfarorg/Articles/On_The_Hill/2013/fact%20sheet%20Syringe%20Exchange%20031913.pdf).
- 82 *ibid.*
- 83 Kaiser Family Foundation (KFF). (2019, February 7). Black Americans and HIV/AIDS: The basics. Retrieved from <https://www.kff.org/hiv/aids/fact-sheet/black-americans-and-hiv-aids-the-basics/>.
- 84 CDC. (2019, November 12). HIV and youth. Retrieved from <https://www.cdc.gov/hiv/group/age/youth/index.html>.
- 85 *ibid.*
- 86 *ibid.*
- 87 *ibid.*
- 88 *ibid.*
- 89 *ibid.*
- 90 KFF. (2018, June 1). Abstinence education programs: Definition, funding, and impact on teen sexual behavior. Retrieved from <https://www.kff.org/womens-health-policy/fact-sheet/abstinence-education-programs-definition-funding-and-impact-on-teen-sexual-behavior/>.
- 91 Garcia, M. (2015, November 17). How historically black colleges and universities are trying to stop the spread of HIV at their schools and beyond. Retrieved from <https://www.hivplusmag.com/case-studies/youth/2013/02/04/black-colleges-and-hiv?pg=full>
- 92 *ibid.*
- 93 *ibid.*
- 94 *ibid.*
- 95 *ibid.*
- 96 *ibid.*
- 97 The Well Project. (2019, April 3). Birth control and HIV/AIDS. Retrieved from <https://www.thewellproject.org/hiv-information/birth-control-and-hiv>.
- 98 American Pregnancy Association. (2019, October 15). HIV/AIDS during pregnancy. Retrieved from <https://americanpregnancy.org/pregnancy-complications/hiv-aids-during-pregnancy/>.
- 99 *ibid.*
- 100 *ibid.*
- 101 CDC. (2019, November 12). HIV and pregnant women, infants and children. Retrieved from <https://www.cdc.gov/hiv/group/gender/pregnantwomen/index.html>.
- 102 *ibid.*
- 103 *ibid.*
- 104 KFF. (2019, March 25). The HIV/AIDS epidemic in the United States: The basics. Retrieved from <https://www.kff.org/hiv/aids/fact-sheet/the-hiv-aids-epidemic-in-the-united-states-the-basics/>.
- 105 CDC. (2019, November 12). HIV treatment as prevention. Retrieved from <https://www.cdc.gov/hiv/risk/art/index.html>.
- 106 Nwangwu-Ike, N. (2018, October 1). Racial and ethnic differences in viral suppression among HIV-positive women in care. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/30212433>.
- 107 KFF. (2019, February 7). Black Americans and HIV/AIDS: The basics. Retrieved from <https://www.kff.org/hiv/aids/fact-sheet/black-americans-and-hiv-aids-the-basics/>.
- 108 The Patient Protection and Affordable Care Act, P.L. 111-148. Retrieved from <https://www.healthcare.gov/where-can-i-read-the-affordable-care-act/>.
- 109 U.S. Preventive Services Task Force. (2019, June 11). Final recommendation statement: Screening for HIV infection. Retrieved from <https://www.uspreventiveservicestaskforce.org/Announcements/News/Item/final-recommendation-statement-screening-for-hiv-infection>.
- 110 KFF. (2019, March 28). Medicaid's Role for Women. Retrieved from <https://www.kff.org/womens-health-policy/fact-sheet/medicaids-role-for-women/>.
- 111 National Partnership for Women and Families. (2019, April). Black women experience pervasive disparities in access to health insurance. Retrieved from <http://www.nationalpartnership.org/our-work/resources/health-care/black-womens-health-insurance-coverage.pdf>.
- 112 KFF. (2019, October 1). Medicaid and HIV. Retrieved from <https://www.kff.org/hiv/aids/fact-sheet/medicaid-and-hiv/>.
- 113 National Federation of Independent Business v. Sebelius. 567 U.S. 519 (2012). Retrieved from <https://www.law.cornell.edu/supremecourt/text/11-393>.
- 114 KFF. (2019, November 15). Status of state action on ACA Medicaid expansion. Retrieved from <https://www.kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>.
- 115 KFF. (2019, October 1). Medicaid and HIV. Retrieved from <https://www.kff.org/hiv/aids/fact-sheet/medicaid-and-hiv/>.
- 116 Pear, Robert. (2019, February 5). Trump plan to stop HIV will target "hot spot" areas. Retrieved from <https://www.nytimes.com/2019/02/05/us/politics/trump-hiv-aids-plan.html>.
- 117 HHS. (2018, January 11). Regarding opportunities to promote work and community engagement among Medicaid beneficiaries. Retrieved from <https://www.medicaid.gov/federal-policy-guidance/downloads/smd18002.pdf>.
- 118 Scott, Dylan. (2018, December 18). 16,932 people have lost Medicaid coverage under Arkansas' work requirements. Retrieved from <https://www.vox.com/policy-and-politics/2018/12/18/18146261/arkansas-medicaid-work-requirements-enrollment>.
- 119 Goldstein, Amy. (2019, March 27). Federal judge blocks Medicaid work requirements in Kentucky and Arkansas. Retrieved from [https://www.washingtonpost.com/national/health-science/federal-judge-blocks-medicaid-work-requirements-in-kentucky-and-arkansas/2019/03/27/34dab2c8-50a8-11e9-a3f7-78b7525a8d5f\\_story.html](https://www.washingtonpost.com/national/health-science/federal-judge-blocks-medicaid-work-requirements-in-kentucky-and-arkansas/2019/03/27/34dab2c8-50a8-11e9-a3f7-78b7525a8d5f_story.html).
- 120 Rabinowitz, Kate. (2019, March 12). What Trump proposed in his 2020 budget. Retrieved from <https://www.washingtonpost.com/graphics/2019/politics/trump-budget-2020/>.

- 121 Center on Budget and Policy Priorities (CBPP). (2019, March 11). 2020 Trump budget: A disturbing vision center on budget and policy priorities. Retrieved from <https://www.cbpp.org/research/federal-budget/2020-trump-budget-a-disturbing-vision>.
- 122 KFF. (2016, October 14). Medicare and HIV. Retrieved from <https://www.kff.org/hiv/aids/fact-sheet/medicare-and-hiv/>.
- 123 *ibid.*
- 124 *ibid.*
- 125 *ibid.*
- 126 *ibid.*
- 127 HHS. (2019, February 6). Proposed rule. Retrieved <https://www.federalregister.gov/documents/2019/02/06/2019-01026/fraud-and-abuse-removal-of-safe-harbor-protection-for-rebates-involving-prescription-pharmaceuticals>.
- 128 HHS. (2019, March 16). Medicare Advantage and Part D drug pricing final rule. Retrieved from <https://www.cms.gov/newsroom/fact-sheets/medicare-advantage-and-part-d-drug-pricing-final-rule-cms-4180-f>.
- 129 Congressional Research Service (CRS). (2015, December 21). The Ryan White HIV/AIDS program: Overview and impact of Affordable Care Act. Retrieved from <https://fas.org/sgp/crs/misc/R44282.pdf>.
- 130 Health Resources and Services Administration (HRSA). (2019, February). About the Ryan White HIV/AIDS program. Retrieved from <https://hab.hrsa.gov/about-ryan-white-hiv-aids-program/about-ryan-white-hiv-aids-program>.
- 131 HRSA. (2019, August). Black/African Americans: Ryan White HIV/AIDS program clients, 2017. Retrieved from <https://hab.hrsa.gov/sites/default/files/hab/Publications/factsheets/population-factsheet-baa.pdf>.
- 132 *ibid.*
- 133 Kopan, Tal. (2018, September 20). Trump admin moves \$260M from cancer research, HIV/AIDS and other programs to cover custody of immigrant children. Retrieved from <https://www.cnn.com/2018/09/20/politics/hhs-shifting-money-cancer-aids-immigrant-children/index.html>.
- 134 Kopan, Tal. (2018, September 20). Trump admin moves \$260M from cancer research, HIV/AIDS and other programs to cover custody of immigrant children. Retrieved from <https://www.cnn.com/2018/09/20/politics/hhs-shifting-money-cancer-aids-immigrant-children/index.html>.
- 135 HHS. (2016, May 18). Nondiscrimination in health programs and activities. Retrieved from [https://www.federalregister.gov/documents/2016/05/18/2016-11458/nondiscrimination-in-health-programs-and-activities?utm\\_campaign=subscription+mailing+list&utm\\_medium=email&utm\\_source=federalregister.gov](https://www.federalregister.gov/documents/2016/05/18/2016-11458/nondiscrimination-in-health-programs-and-activities?utm_campaign=subscription+mailing+list&utm_medium=email&utm_source=federalregister.gov).
- 136 *ibid.*
- 137 HHS. (2019, June 14). Nondiscrimination in health programs and activities. Retrieved from <https://www.federalregister.gov/documents/2019/06/14/2019-11512/nondiscrimination-in-health-and-health-education-programs-or-activities>.
- 138 UNAIDS. Global HIV & AIDS statistics – 2019 fact sheet. Retrieved from <https://www.unaids.org/en/resources/fact-sheet>.
- 139 *ibid.*
- 140 U.S. Department of State. PEPFAR 2019 annual report to Congress. Retrieved from <https://www.state.gov/wp-content/uploads/2019/09/PEPFAR2019ARC.pdf>.
- 141 U.S. Department of State. (2018, November). PEPFAR latest global results. Retrieved from <https://www.state.gov/wp-content/uploads/2019/08/2018-PEPFAR-Latest-Global-Results.pdf>.
- 142 KFF. (2019, May 31). Breaking down the U.S. global health budget by program area. Retrieved from <https://www.kff.org/global-health-policy/fact-sheet/breaking-down-the-u-s-global-health-budget-by-program-area/#HIV-PEPFAR>.
- 143 KFF. (2019, August 2). The U.S. President's emergency plan for AIDS relief (PEPFAR). Retrieved from <https://www.kff.org/global-health-policy/fact-sheet/the-u-s-presidents-emergency-plan-for/>.
- 144 KFF. (2019, March 12). Trump Administration's FY 2020 budget request calls for cuts to global health, including bilateral HIV spending, while increasing funding for domestic HIV efforts. Retrieved from <https://www.kff.org/news-summary/trump-administrations-fy20-budget-request-calls-for-cuts-to-global-health-including-bilateral-hiv-spending-while-increasing-funding-for-domestic-hiv-efforts/>.
- 145 Green, Andrew. (2019, June 11). What's behind PEPFAR's funding cut threats? Retrieved from <https://www.devex.com/news/what-s-behind-pepfar-s-funding-cut-threats-95053>.
- 146 Evertz, Scott. (2010, January 13). How ideology trumped science: Why PEPFAR has failed to meet its potential. Retrieved from <https://www.americanprogress.org/issues/healthcare/reports/2010/01/13/7214/how-ideology-trumped-science/>.
- 147 CDC. (2019, November 12). HIV and African Americans. Retrieved from <https://www.cdc.gov/hiv/group/racialethnic/africanamericans/index.html>.
- 148 Hernandez, D. & Swope, C. (2019). Housing as a platform of health and equity: evidence and future directions. *American Journal of Public Health*. 109(10). 1363-1369.
- 149 Carter, M. (2019, May 17). Rapid rehousing support for homeless people living with HIV improves housing and HIV outcomes. Retrieved from <http://www.aidsmap.com/news/may-2019/rapid-rehousing-support-homeless-people-living-hiv-improves-housing-and-hiv-outcomes>
- 150 Aidala, A. (2016, July 27). Housing instability presents barriers to HIV treatment. Retrieved from <https://housingmatters.urban.org/research-summary/housing-instability-presents-barriers-hiv-treatment>
- 151 *ibid.*
- 152 *ibid.*
- 153 *ibid.*
- 154 *ibid.*
- 155 The Well Project. (2019, January 9). Housing options for people living with HIV in the U.S. Retrieved from <https://www.thewellproject.org/hiv-information/housing-options-people-living-hiv-us>
- 156 *ibid.*
- 157 *ibid.*
- 158 *ibid.*
- 159 *ibid.*
- 160 *ibid.*
- 161 CDC. (2011, August 12). Characteristics associated with HIV infection among heterosexuals in urban areas with high AIDS prevalence – 24 cities, United States, 2006-2007. Retrieved from <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6031a1.htm>.
- 162 *ibid.*
- 163 Positive Justice Project. (2017, February 13). Consensus statement on criminalization of HIV in the United States. Retrieved from [http://www.hivlawandpolicy.org/sites/default/files/PJP%20Consensus%20Statement%20with%20Endorsers%20%28updated%202.13.17%29\\_0.pdf](http://www.hivlawandpolicy.org/sites/default/files/PJP%20Consensus%20Statement%20with%20Endorsers%20%28updated%202.13.17%29_0.pdf).
- 164 Positive Justice Project. (2017, February 13). Consensus statement on criminalization of HIV in the United States. Retrieved from [http://www.hivlawandpolicy.org/sites/default/files/PJP%20Consensus%20Statement%20with%20Endorsers%20%28updated%202.13.17%29\\_0.pdf](http://www.hivlawandpolicy.org/sites/default/files/PJP%20Consensus%20Statement%20with%20Endorsers%20%28updated%202.13.17%29_0.pdf).
- 165 Positive Justice Project. (2017, February 13). Consensus statement on criminalization of HIV in the United States. Retrieved from [http://www.hivlawandpolicy.org/sites/default/files/PJP%20Consensus%20Statement%20with%20Endorsers%20%28updated%202.13.17%29\\_0.pdf](http://www.hivlawandpolicy.org/sites/default/files/PJP%20Consensus%20Statement%20with%20Endorsers%20%28updated%202.13.17%29_0.pdf).
- 166 *ibid.*
- 167 *ibid.*
- 168 *ibid.*
- 169 *ibid.*
- 170 *ibid.*
- 171 *ibid.*
- 172 *ibid.*
- 173 *ibid.*
- 174 *ibid.*
- 175 Center for HIV Law & Policy. (2016, February 7). Studies Show HIV Criminalization Laws Disproportionately Punish People of color. Retrieved from <https://www.hivlawandpolicy.org/news/studies-show-hiv-criminalization-laws-disproportionately-punish-people-color>
- 176 *ibid.*
- 177 *ibid.*
- 178 Center for HIV Law & Policy. Racial Justice. Retrieved from <http://www.hivlawandpolicy.org/issues/racial-justice>



- 179 Center for HIV Law & Policy. (2016, February 7). Studies Show HIV Criminalization Laws Disproportionately Punish People of color. Retrieved from <https://www.hivlawandpolicy.org/news/studies-show-hiv-criminalization-laws-disproportionately-punish-people-color>
- 180 *ibid.*
- 181 Positive Women's Network. Ending HIV criminalization fact sheet. Retrieved from <https://www.pwn-usa.org/issues/policy-agenda/ending-criminalization/ending-hiv-criminalization/>.
- 182 Center for HIV Law & Policy. Racial justice. Retrieved from <http://www.hivlawandpolicy.org/issues/racial-justice>.
- 183 Positive's Women's Network. Ending HIV criminalization fact sheet. Retrieved from <https://www.pwn-usa.org/issues/policy-agenda/ending-criminalization/ending-hiv-criminalization/>
- 184 *ibid.*
- 185 Positive Women's Network. Factsheet: criminalization as violence against women living with HIV. Retrieved from <https://www.pwn-usa.org/doi2016/factsheet-doa2016/>.
- 186 *ibid.*
- 187 *ibid.*
- 188 *ibid.*
- 189 (Moodie-Mills & Robinson, 2012, July 27). HIV/AIDS inequality: structural barriers to prevention, treatment, care in communities of color. Retrieved from [https://cdn.americanprogress.org/wp-content/uploads/issues/2012/07/pdf/hiv\\_community\\_of\\_color.pdf](https://cdn.americanprogress.org/wp-content/uploads/issues/2012/07/pdf/hiv_community_of_color.pdf)
- 190 *ibid.*
- 191 *ibid.*
- 192 Mitchum, P. (2013, July 16). Study: HIV criminalization laws disparately impact transgender people. Retrieved from <https://thinkprogress.org/study-hiv-criminalization-laws-disparately-impact-transgender-people-db251f7d76f/>.
- 193 *ibid.*
- 194 *ibid.*
- 195 *ibid.*
- 196 *ibid.*
- 197 *ibid.*
- 198 U.S. Department of Justice. (2014, March 15). Best practices guide to reform HIV-specific criminal laws to align with scientifically-supported factors. Retrieved from <https://www.ada.gov/hiv/HIV-guide-reform-crim.pdf>
- 199 *ibid.*
- 200 *ibid.*
- 201 *ibid.*
- 202 Positive's Women's Network. Ending HIV criminalization fact sheet. Retrieved from <https://www.pwn-usa.org/issues/policy-agenda/ending-criminalization/ending-hiv-criminalization/>
- 203 *ibid.*
- 204 *ibid.*
- 205 *ibid.*
- 206 *ibid.*
- 207 *ibid.*
- 208 *ibid.*
- 209 *ibid.*
- 210 *ibid.*
- 211 *ibid.*
- 212 *ibid.*
- 213 *ibid.*
- 214 *ibid.*
- 215 Positive Women's Network. (2019). HIV criminalization fact sheet. Retrieved from <https://www.pwn-usa.org/wp-content/uploads/2019/02/HIV-Criminalization-Factsheet-v1.pdf>.
- 216 Center for HIV Law & Policy. Immigration. Retrieved from <https://www.hivlawandpolicy.org/issues/immigration>
- 217 *ibid.*
- 218 *ibid.*
- 219 McKinnon, F. (2006, October 1). Immigration and HIV. Retrieved from <https://www.thebodypro.com/article/immigration-hiv>.
- 220 *ibid.*
- 221 *ibid.*
- 222 *ibid.*
- 223 *ibid.*
- 224 *ibid.*
- 225 *ibid.*
- 226 *ibid.*
- 227 Center for HIV Law & Policy. Immigration. Retrieved from <http://www.hivlawandpolicy.org/issues/immigration>
- 228 *ibid.*
- 229 Jungwirth, B. (2017, January 2). Immigrant women face many barriers to HIV testing and care. Retrieved from <https://www.thebody.com/article/immigrant-women-face-many-barriers-to-hiv-testing->
- 230 *ibid.*
- 231 *ibid.*
- 232 Holmes, T. (2018, April 27). Black immigrants and HIV: prevention and treatment strategies that work. Retrieved from <https://blackaids.org/blog/black-immigrants-and-hiv-prevention-and-treatment-strategies-that-work/>.
- 233 *ibid.*
- 234 *ibid.*
- 235 *ibid.*
- 236 *ibid.*
- 237 *ibid.*
- 238 *ibid.*
- 239 *ibid.*
- 240 *ibid.*
- 241 *ibid.*
- 242 *ibid.*
- 243 *ibid.*
- 244 *ibid.*
- 245 *ibid.*
- 246 *ibid.*
- 247 Jungwirth, B. (2017, January 2). Immigrant women face many barriers to HIV testing and care. Retrieved from <https://www.thebody.com/article/immigrant-women-face-many-barriers-to-hiv-testing->
- 248 *ibid.*
- 249 *ibid.*
- 250 Holmes, T. (2018, April 27). Black immigrants and HIV: prevention and treatment strategies that work. Retrieved from <https://blackaids.org/blog/black-immigrants-and-hiv-prevention-and-treatment-strategies-that-work/>.
- 251 *ibid.*
- 252 *ibid.*
- 253 *ibid.*
- 254 Assuncao, M. (2019, September 26). Human rights groups are calling for release of HIV-positive and LGBTQ people from ICE detention, abuse is well documented. New York Daily News. Retrieved from <https://www.nydailynews.com/news/national/ny-ice-customs-border-protections-lgbtq-people-living-hiv-complaint-20190926-gx2fkun4vnb4lh65u54rtytnssi-story.html>.
- 255 *ibid.*
- 256 *ibid.*
- 257 *ibid.*
- 258 *ibid.*
- 259 Immigration Equality. HIV band end & HIV-based immigration. Retrieved from <https://www.immigrationequality.org/get-legal-help/our-legal-resources/visa-questions/hiv-ban-hiv-based-immigration-applications/#.XeYYZtVOnb0>.
- 260 Hayoun, M. (2019, August 1). Customs and border protection is separating families based on HIV status. Retrieved from <https://psmag.com/social-justice/customs-and-border-protection-is-separating-families-based-on-hiv-status>.
- 261 *ibid.*
- 262 Gibson, D. (2018, July 3). For immigrants living with HIV, an impossible choice between viral suppression and deportation. Retrieved from <https://www.thebody.com/article/for-immigrants-living-with-hiv-an-impossible-choic>.
- 263 *ibid.*
- 264 *ibid.*
- 265 *ibid.*
- 266 *ibid.*
- 267 *ibid.*
- 268 *ibid.*
- 269 Alvarenga, G. (2019, August 26). Using HIV to justify immigration bans isn't new. Here's the 35-year history. Retrieved from <https://www.thebody.com/article/using-hiv-to-justify-immigration-bans-isnt-new-heres-the-35-year-history>.
- 270 *ibid.*



## About On Our Own Terms

Launched in 2017 by the Black Women's Health Imperative (BWHI) in response to the need for Black women-centered HIV prevention, On Our Own Terms (OOOT) is a national strategy to improve sexual health, HIV outcomes, and overall wellness for Black women. This initiative supports collaborations, solutions, and policies guided by the lived realities of Black Women. OOOT, BWHI,

and strategic partners are creating a platform where the voices, faces, and lived realities will be attached to HIV-related statistics in our communities. With its partners, OOOT is building a strategic and comprehensive HIV prevention agenda to integrate the lived experiences of Black women into HIV prevention research, policy development, and program practice.

## STEERING COMMITTEE



## ADVISORY COUNCIL





A close-up portrait of a Black woman with voluminous, curly brown hair. She is smiling broadly, showing her teeth, and looking upwards and to the right. She is wearing a light blue button-down shirt. The background is a plain, light-colored wall.

### About the Black Women's Health Imperative

The Black Women's Health Imperative (BWHI) is a national non-profit organization dedicated to advancing health equity and social justice for Black women, across the lifespan, through policy, advocacy, education, research, and leadership development. The organization identifies the most pressing health issues that affect the nation's 22 million Black women and girls and invests in the best of the best strategies and organizations that accomplish its goals. For more information, please visit [www.bwhi.org](http://www.bwhi.org)







**BLACK WOMEN'S**  
HEALTH IMPERATIVE

[www.bwhi.org](http://www.bwhi.org)