HIV Law and Policy in the United States: A Tipping Point

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Summary

The fight to effectively treat and stop the spread of the human immunodeficiency virus (HIV) has made meaningful progress both in the United States and globally. But within the United States that progress has been uneven across various demographic groups and geographic areas, and has plateaued. While scientific advances have led to the development of medicine capable of both treating and preventing HIV, law and policy dictate who will have ready access to these medicines and other prevention techniques, and who will not. Law and policy also play a crucial role in determining whether HIV will be stigmatized, discouraging people from being tested and treated, or will be identified for what it is—a preventable and treatable disease. To make further progress against HIV, the United States must address healthcare disparities, end the criminalization of HIV, and devote additional resources toward combatting HIV stigma and discrimination.

Keywords: HIV, AIDS, public health, LGBT rights, racial justice, political activism, LGBT politics

Uneven Progress in the Fight Against HIV

According to Centers for Disease Control (CDC) estimates available in mid 2019, over 1.1 million people in the United States are living with HIV, with around one million people diagnosed with HIV. This means about 1 in 7 people living with HIV are unaware that they have the disease (CDC, 2019a; DHHS, 2020). In total, around 700,000 people have died from HIV/AIDS in the United States since the start of the epidemic in the 1980s. While the annual incidence of new HIV infection had been steadily decreasing, beginning in around 2013, the number of estimated new infections began to level off at around 38,000 to 39,000 per year (CDC, 2019a; DHHS, 2020). This plateau persists because effective prevention and treatment efforts are not reaching certain populations, in part because of persistent stigma and discrimination. In other words, the impact of the disease continues to be unevenly distributed, with higher concentrations among certain racial and sexual minorities (CDC, 2018a, 2020a).

Overall, black people have the highest rate of HIV prevalence (the number of people living with HIV) as compared to other racial and ethnic groups, and the rate of new infection among black people continues to be disproportionately high. For example, at the end of 2016, of the estimated 1,140,400 people over the age of 12 living with HIV, 476,100 of them were black. In 2016, black people represented roughly 12% of the population, but they represented 42.4% of...
all new HIV infections (CDC, 2019a). Put differently, in 2016, the rate of new infections was 8.9 times higher among black people than among white people. These disproportionate trends continued with respect to diagnosed HIV infections in 2018 (CDC, 2020a).

Black men who have sex with men (MSM) are particularly vulnerable—of the almost 39,000 people infected with HIV in 2016, black gay or bisexual men accounted for around 10,000 of the infections, with about 8,300 Hispanic/Latino gay or bisexual men and 6,700 white gay or bisexual men being infected. In 2016, Hispanics/Latinos represented 18% of the population but accounted for 27% of HIV diagnoses. Black and Latino populations also have the highest rates of undiagnosed HIV infection, stymieing those communities’ ability to get treated for the infection. Black women are also disproportionately impacted—in 2016, their rate of new infections was 15.1 times the rate for white females. Geographically, rates of new infection in 2016 were highest in the South (CDC, 2019a). The Deep South has also had the highest HIV death rates (Reif, Safley, McAllaster, Wilson, & Whetten, 2017).

In addition to racial and geographic disparities, MSM continue to bear the brunt of the epidemic. In 2016, 68% of all new infections occurred as a result of male-to-male sexual contact, with 84% of all male infections resulting from male-to-male sexual contact. Similarly, among diagnosed HIV infections in 2018, 69% were among MSM. (CDC, 2020a). As noted, among MSM, racial disparities persist. From 2010 to 2016, new, annual HIV infections among white MSM decreased, remained stable among black MSM, and increased among Latino MSM (CDC, 2019a).

As highlighted, the decrease in the overall number of new infections in the United States has plateaued. More dramatic progress is curtailed, in part, by the so-called treatment cascade or care continuum. The treatment cascade refers to the fact that, as of 2016, of the million plus people living with HIV in the United States, only about 86% (or 1 in 7) have actually been diagnosed with the virus, and only 64% were in receipt of care (defined as at least one CD4 or viral load test in a year-long period). Only 49% were retained in care (defined as two or more CD4 or viral load tests at least 3 months apart in an annual period). Ultimately, only 53% of all people living with HIV had achieved viral suppression, which is defined as the achievement of very low levels of HIV in someone’s blood (CDC, 2019c).

Viral suppression is critical to the health and well-being of someone living with HIV—that is, critical to their successful treatment. In addition, when the level of virus is suppressed enough that it becomes undetectable, HIV is also untransmittable sexually from someone carrying the disease to a sexual partner. As explained by multiple national and international public health authorities, U = U—undetectable = untransmittable (Bruner, 2019). Therefore, treatment of people with HIV is critical in the fight to stop its spread—a concept known as “treatment as prevention” (Office of National AIDS Policy [ONAP], 2015). Indeed, according to an analysis published in 2019, about 80% of new infections in the United States in 2016 were transmitted from the roughly 40% of people living with HIV who either did not know of their infection or who had been diagnosed but were not receiving care (Zihao, Purcell, Samson, Hayes, & Hall, 2019). Similarly, according to an analysis published in 2015, 9 in 10 new infections in 2009 came from people that either had not been diagnosed or had been diagnosed but were not retained in care (Skarbinski et al., 2015). In other words, treatment and prevention are intimately linked and if the disease is to be stopped from spreading, it is essential that those already living with HIV be diagnosed and treated.
Therefore, to the extent that the slope of the treatment cascade remains extreme—with only half of people living with HIV virally suppressed—the ability of the disease to spread remains very real. Based on this relationship between treatment and prevention, the Joint United Nations Programme on HIV and AIDS (UNAIDS) set the ambitious 90-90-90 goal to be achieved by 2020—90% of people living with HIV will know their status, at least 90% all people diagnosed will receive sustained antiretroviral therapy, and 90% of all those receiving antiretroviral therapy will have achieved viral suppression (UNAIDS, 2017). However, while progress has been made toward the goal, achieving the 90-90-90 benchmarks by 2020 now seems out of reach.

**Two Steps Forward: The Reasons for Progress**

The progress that has occurred is the result of tireless activism and education, innovative public health strategies, antidiscrimination law reform, growing recognition that treatment of people living with HIV is an important component in the fight to prevent the disease from spreading, and the deployment of important medical advances.

**Awareness and Education**

HIV is a highly preventable disease. Informing people about how HIV is transmitted, how it is not transmitted, and how to prevent transmission has been critical in the battle to stem the tide of the epidemic. Educating the public about the disease has helped people protect themselves, and it has also helped to decrease stigma and misunderstanding regarding those living with the disease. Most commonly, people contract HIV through anal or vaginal sex without use of a condom with someone who is HIV-positive but does not have an undetectable viral load or through sharing a needle or syringe for injection drug use with someone who is HIV-positive. HIV cannot be spread through casual contact, such as sharing a toilet seat, sharing a drink, or kissing (CDC, 2019d). The use of condoms as a means of preventing the spread of HIV during sex is highly effective (Henn, 2018). Furthermore, as is discussed in more detail, the daily implementation of so-called pre-exposure prophylaxis (PrEP)—taking a particular antiretroviral (ARV) medication—by someone who does not have HIV can also dramatically reduce the risk that the person taking PrEP will contract HIV through unprotected sex.

However, despite widespread efforts to educate the public about how HIV is spread, is not spread, and can be prevented, certain myths stubbornly persist. According to a survey by the Kaiser Family Foundation (KFF) in 2012, one third of Americans surveyed harbored at least one misconception about HIV transmission. For example, 27% of those surveyed did not know that HIV cannot be transmitted through sharing a drinking glass (Washington Post/KFF, 2012). Moreover, according to a 2019 KFF poll, only 42% of the public were aware of PrEP, the prescription medication that can dramatically lower the risk of getting HIV. Only 15% of the public were aware that the use of antiretroviral (ARV) drugs to treat people with HIV was also very effective at preventing the spread of the virus—the aforementioned concept of “treatment as prevention” (Kirzinger, Lopes, Wu, & Brodie, 2019). As discussed, when an individual undergoes ARV treatment and their viral load becomes undetectable, the virus is then untransmittable to others sexually.
These statistics underscore the continued need for education, awareness, and publicity regarding the contours of the HIV epidemic. According to the 2012 KFF survey, visibility of the epidemic had decreased meaningfully compared to the prior decade, confirming that renewed efforts, funding, and vigilance are needed with regard to HIV education (Washington Post/KFF, 2012).

**Testing**

Testing remains another critical first line of defense for treatment and prevention of the disease. It stands to reason that, without testing, diagnosis may be delayed, limiting the initiation of early ARV treatment that may reduce morbidity and mortality and simultaneously reduce the risk of further HIV transmission. Moreover, people who are not aware that they have HIV may not take steps to prevent the spread of the disease to others and may, for example, continue to engage in unprotected sex.

Consequently, in 2006, the CDC began recommending that all adults (not just those deemed to be engaging in high-risk behavior) who visit their healthcare provider be provided with so-called routine “opt-out testing,” allowing for consent as part of a general laboratory consent form unless the patient declines, rather than a separate, specific “opt-in” consent to HIV testing (Branson et al., 2006). Consequently, nearly every state has removed any requirement for a separate consent to HIV testing. The change in policy was designed to increase the number of people being tested—and therefore diagnosed and treated as soon as possible—at the same time that it reduced stigma associated with HIV by no longer singling it out as a somehow distinct, particularly significant, kind of laboratory test. Those engaged in behavior putting them at higher risk of contracting HIV, such as men who have unprotected sex with other men of unknown status and people who inject drugs (PWID), are advised to seek testing more frequently—at least once a year (Branson et al., 2006). To be clear, although HIV disproportionately impacts MSM relative to other groups, roughly 90% of queer men do not have HIV and, as Robinson and Frost emphasized, MSM identity is a “weak proxy for being HIV positive” (Robinson & Frost, 2018). Put differently, it is certain behavior (e.g., unprotected sex with partners of unknown status), not an MSM identity in and of itself, that puts an individual at higher risk. Nevertheless, the CDC recommends that sexually active MSM be screened at least annually, and perhaps more frequently, considering the patient’s individual risk factors (DiNenno et al., 2017).

However, despite the CDC’s 2006 revised recommendations for more routine, opt-out testing, according to an analysis released by the CDC in 2018, only 39.6% of adults surveyed had ever been tested for HIV and only 62.2% of those reported to have engaged in HIV-related risk behaviors over the preceding 12 months were ever tested for HIV. Moreover, the percentage of persons ever tested and the interval since their last test remained unchanged between 2006 and 2016, suggesting that HIV screening frequency for those at risk for HIV has not improved meaningfully since 2006—the year the CDC announced its more aggressive testing guidelines (Pitasi et al., 2018). Similarly, according to a 2014 survey conducted by KFF, only about half of US adults had ever been tested for HIV, with only 16% being tested in the year prior to the survey (KFF, 2014). According to the CDC, the continued struggles to, in effect, enact universal testing suggest that efforts need to be taken to expand testing in nonclinical settings through, for example, social network strategies and home testing.
Fortunately, accurate and increasingly accessible testing techniques continue to be developed. The most accurate kinds of tests are clinical/laboratory blood tests that use the presence of anti-HIV antibodies, HIV viral proteins, or viral RNA (or some combination) to diagnose HIV infection. Importantly, even the widely used laboratory tests have what is called a “window period”—a period of time after exposure where the test is unable to determine whether or not a person has been infected. Put differently, it is impossible to detect HIV immediately after infection—even in a clinical setting (DHHS, 2018). The range of the window period varies depending on the specific kind of test performed and each individual’s response to the virus, but generally speaking if a person is clinically tested 3 months after exposure and the test is negative, there is a high degree of confidence that the person is not infected with HIV. If the person is tested within 3 months of potential exposure and the result is negative, it is recommended that the person be retested after 3 months have elapsed since exposure to confirm the negative result. Clinical test results are usually available within a few days to a few weeks after testing.

In addition to laboratory blood tests, in 2012 the FDA approved an in-home HIV test kit—the OraQuick In-Home HIV test. This test uses an oral swab sample to provide results within 20 minutes. Because this oral, in-home test is less accurate than laboratory blood tests, results should be confirmed with follow-up laboratory testing. However, the in-home test does provide a more accessible form of testing for those unable to seek, or deterred from seeking, laboratory blood testing and is one potential gateway for increasing universal testing outside of the clinical setting (CDC, 2020c).

Prevention

While testing is key to the initiation of treatment and is an important tool for further prevention, prevention is not just the responsibility of those already diagnosed with HIV. It is everyone’s responsibility, and there are an increasing number of scientifically proven methods that can be used to decrease the chances of transmission.

Condoms

Condoms—when used consistently and correctly—are a highly effective way of preventing the transmission of HIV and other sexually transmitted diseases (Henn, 2018). In fact, when used consistently and correctly, penis condoms are the only contraceptive that provides protection against both pregnancy and most sexually transmitted diseases, including HIV. Moreover, they are an incredibly cost-effective form of prevention and, of course, significantly less expensive for individuals and governments than the cost of HIV antiretroviral treatment. Notwithstanding condoms’ efficacy and importance, studies continue to suggest that condom use remains spotty at best (Copen, 2017). As such, the CDC endorses structural-level condom distribution programs that include wide distribution of free condoms accompanied by social market campaigns promoting and normalizing condom use, with more targeted, high-intensity risk-reduction interventions for individuals engaged in higher risk activities. Overall, the CDC emphasizes that condom distribution programs should aim to make condoms available, accessible, and acceptable (CDC, 2019e).
PrEP

In addition to condom use, daily use of PrEP can reduce the risk of getting HIV through sex by over 90%. While PrEP is less effective at preventing the spread of HIV through injection drug use, it can still reduce the risk of HIV by 70%. Importantly, PrEP does not prevent other sexually transmitted diseases or pregnancy, and so it should be combined with condom use (CDC, 2019b). Truvada was first approved by the Food and Drug Administration (FDA) for use as PrEP in adults in 2012, and for anyone—including adolescents—weighing 35 kg or more in 2018. A second drug called Descovy was approved by the FDA for use as PrEP for those weighing 35 kgs or more in 2019 (though Descovy is not indicated for people at risk of HIV from receptive vaginal sex). Federal guidelines are that prescription of PrEP is indicated for people at high risk of HIV, including, among others: (a) anyone who is HIV-negative and in an ongoing relationship with an HIV-positive partner, (b) gay or bisexual men not in a mutually monogamous relationship with an HIV-negative person and who have had anal sex without using a condom in the last 6 months, (c) heterosexual men or women who do not regularly use condoms during sex with partners of unknown HIV status who are at substantial risk of HIV infection, and (d) people who have injected drugs in the past 6 months while sharing injection equipment (CDC, 2019b)

Based on these behavioral risk factors, the CDC estimates that more than 1 million Americans have indications for PrEP prescriptions. According to a study published by the CDC’s Division of HIV/AIDS Prevention in 2018 based on 2015 data, of the 1.1 million adults with indications for PrEP, over 800,000 of them were MSM, over 500,000 were black, and over 280,00 were Latino (Smith, Van Handel, & Grey, 2018).

However, despite PrEP’s efficacy and promise, PrEP uptake has—overall—been quite limited. For example, in 2016, according to some estimates, only about 77,000 people were using PrEP in the United States, notwithstanding that over 1 million people’s behavior suggested they should take PrEP to prevent contracting HIV (AIDSVu, 2019). And while PrEP use has been steadily increasing (for example, according to one estimate, use increased by about 30% each year from 2016 to 2018), access to PrEP remains extremely uneven and limited in part because of its cost and disproportionate lack of healthcare coverage generally for marginalized communities. For example, communities of color and Southern states continue to have disproportionate need for PrEP but penetration of PrEP in these communities has been limited (CDC, 2018b; Ojikutu et al., 2018). Similarly, notwithstanding that women account for one of every five new HIV diagnoses, PrEP uptake among women (especially black women) has been very low (Bradley & Hoover, 2019).

As Smith et al. (2018) concluded, “Urgent scaling up of PrEP delivery for blacks (in all transmission risk groups) is the highest priority, both because of the high number and proportion estimated to have indications for PrEP and because of their current very low utilization of it.” The Smith study also confirmed that “MSM (of all race/ethnicities) remain a priority for PrEP delivery” (Smith et al., 2018). Barriers to PrEP uptake and saturation include insufficiently effective communication and education by public health authorities to indicated populations on the drug’s existence, efficacy, and availability; insufficient education of healthcare providers on how to identify patients who may benefit from PrEP; and cost of both the medication and associated healthcare visits and labs (AIDSVu, 2018).
A monthly prescription for Truvada can cost as much as $2,000, and although many insurers and Medicaid cover the drug when it is prescribed, a person still requires insurance and access to a provider willing to prescribe PrEP. As such, the CDC has begun providing targeted funding to health departments and community-based organizations to expand access for those indicated for PrEP. The CDC has also issued clinical guidelines to help healthcare providers properly identify those in need of a PrEP prescription. The FDA approved a generic version of Truvada manufactured by Teva Pharmaceuticals in 2017, and it will be available on the market in the later part of 2020 (Straube, 2019). However, time will tell whether this has a dramatic impact on the price of PrEP in the United States, because competition will still be limited to just two manufacturers. In addition, in May 2019, Truvada manufacturer Gilead announced an agreement with the U.S. Department of Health & Human Services (DHHS) to donate PrEP for up to 200,000 uninsured people for 11 years (DHHS, 2019d). In another positive development, in June 2019, the U.S. Preventative Services Task Force (USPSTF) gave PrEP an “A” recommendation, finding convincing evidence that PrEP is of substantial benefit in reducing HIV transmission in persons at high risk of infection (USPSTF, 2019). Consequently, under the Affordable Care Act (ACA), individuals on private insurance who are prescribed PrEP have a compelling argument that PrEP constitutes a preventative services which must be covered. In short, while certain steps are being taken to make PrEP more accessible, distribution to those in critical need remains relatively limited.

Syringe and Needle Exchanges

As highlighted by the outbreak of HIV among PWID in Scott County, Indiana, in 2014, sharing needles and syringes for drug use remains a prevalent form of HIV transmission (Gonsalves & Crawford, 2018). PWID account for about 1 in 10 HIV diagnoses in the United States (Wejnert et al., 2016). As such, clean syringe and needle exchanges represent an important form of harm reduction that can help prevent the spread of HIV among PWID, such as the outbreak that occurred in Indiana. While the CDC recognizes that sterile needle and syringe exchange programs are an important component of a comprehensive effort to prevent the spread of HIV, federal funding for such programs is limited. Although federal funds can—upon request—be used by state and local health departments for components of a comprehensive syringe services program, the funds cannot be used to purchase sterile needles or syringes that will be used for illegal injection drug use. At times, the CDC has called for an increase in support for syringe service programs, particularly in rural areas where the risk of outbreak from injection drugs is high and provision of harm reduction services is low (CDC, 2020b; Wejnert et al., 2016).

Indeed, as emphasized by the CDC, there is empirical evidence from certain states and localities that have implemented needle and syringe exchange programs that such programs are both effective at reducing the rate of HIV infection among PWID and are cost-effective (CDC, 2016). According to one study of New York City, the initiation of needle exchanges helped decrease the prevalence of HIV among PWID from 50% in 1992 (when such programs were first legalized/initiated at scale) to 17% in 2002 (Des Jarlais, 2005). In addition to directly decreasing the risk of transmission from used needles and syringes, exchange programs can also serve as intervention points for other public health harm-reduction methods, including condom distribution and HIV testing (CDC, 2020b; Wejnert et al., 2016).
**Post-Exposure Prophylaxis (PEP)**

The most effective techniques for preventing transmission of HIV are those that actually prevent exposure to fluids containing the virus (for example, condoms or needle exchanges) or those that are in place prior to exposure in order to prevent the virus from taking hold (for instance, PrEP). However, even if someone is exposed to body fluids known to be HIV-positive and the exposure represents a substantial risk of transmission, if certain antiretroviral drugs are first taken within 72 hours of the initial exposure and are continued as prescribed for 28 days, infection may be prevented. This prevention technique is known as post-exposure prophylaxis (PEP) and is designed only for emergencies as a prevention measure of last resort (CDC, 2018c, 2019f).

**Treatment and Treatment as Prevention**

In addition to prevention techniques described above, incredible advances in medicine and science—spurred on by HIV/AIDS activism—have enabled several forms of effective medical treatments for an HIV infection if it is contracted. Highly effective antiretroviral drugs have been invented (or repurposed) to fight the development and replication of HIV in the human body. By interfering with the virus's reproduction, antiretroviral drugs help the immune system to remain strong, preventing HIV from causing AIDS (the syndrome characterized by a potentially fatally weak immune system).

Different antiretroviral drugs attack different aspects of HIV and are often prescribed in combinations of two or more drugs, deemed ART (antiretroviral therapy) or HAART (highly active antiretroviral therapy). Colloquially, combined drug therapy is sometimes referred to as a drug “cocktail.” DHHS recommends that individuals diagnosed with HIV begin treatment with ART as soon as possible after diagnosis (DHHS, 2019b).

There are at least six general categories of HIV antiretroviral drugs, but the principal categories are nucleoside reverse transcriptase inhibitors (NRTIs), which block an enzyme called reverse transcriptase that HIV needs to replicate itself; non-nucleoside reverse transcriptase inhibitors (NNRTIs), which bind to and alter reverse transcriptase; protease inhibitors (PIs), which block protease, another enzyme HIV needs to replicate itself; fusion inhibitors, which block HIV from entering CD4 immune system cells; and integrase inhibitors, which block integrase, yet another enzyme HIV needs to copy itself (DHHS, 2019c).

For those with access to HAART, these medicines have transformed HIV from a death sentence to a chronic condition that can be managed, allowing people with HIV to lead long, fulfilling lives. And, as discussed, treatment of HIV not only is critical to saving the lives of those already infected, but also is actually a key prevention technique, because when a person’s viral load is undetectable as a result of HAART, the person doesn’t transmit the virus to others sexually. In other words, treatment of HIV prevents the spread of HIV. The Obama Administration’s National HIV/AIDS Strategy for the United States recognized this important link and that increasing access to treatment was critical to HIV prevention (ONAP, 2010, 2015).
But make no mistake. There was nothing inevitable about the creation of—and access to—antiretroviral drugs in response to the HIV epidemic. When the epidemic first emerged in the United States in the 1980s, the federal government was slow to respond, allowing AIDS to become the leading cause of death for adults between the age of 25 and 44 by 1995 (Altman, 1995). But because of HIV activists, the federal government eventually accelerated its efforts, fast-tracking approval of certain medications and increasing access to them. The government and leaders at the National Institutes of Health (NIH) have openly acknowledged the important role of HIV/AIDS activists in advancing the public health response to the epidemic (NIH, 2009).

In particular, certain programs—such as the Ryan White HIV/AIDS Program—have helped expand access to life-saving medication. Initially passed in 1990 and funded at varying levels since by the federal government, the Ryan White HIV/AIDS Program is the largest federal program specifically targeting people living with HIV, and the third largest overall source of federal funding for HIV care, following Medicare and Medicaid (Health Resources & Services Administration [HRSA], 2019; KFF, 2019). The program provides grants to states and localities for the provision of comprehensive medical care and support services for people living with HIV. As of 2019, more than half a million people received services through the program and, for FY 2019, the program was funded at $2.3 billion. An important component of the Ryan White Program is the AIDS Drug Assistance Program, which provides FDA-approved antiretroviral medications to low-income people living with HIV who have limited or insufficient health insurance coverage from Medicare, Medicaid, or private insurance. Even with the enactment of the ACA in 2010, which expanded access to insurance for people living with HIV by, among other mechanisms, lifting insurance prohibitions on pre-existing conditions and by Medicaid expansion in certain states, the Ryan White Program remains a critical source of funding for HIV treatment and helps fill in important gaps in healthcare coverage for people living with HIV (HRSA, 2019; KFF, 2019).

But despite the partial success of the ACA, Ryan White, Medicare, and Medicaid in extending healthcare and prescription drug treatment to people living with HIV, access to care remains unequal. The divergent progress in combatting the spread and treatment of HIV is not an accident. However, as discussed in the following section, it is the predictable result of different law and policy decisions that exacerbate and contribute to other social inequalities.

One Step Back: Current Policies and Practices Impeding Progress

Despite the tremendous progress that has been made since the outset of the HIV epidemic in the 1980s, significant barriers to care remain. While the Obama Administration put forth a comprehensive National HIV/AIDS Strategy focused on reducing HIV-related health inequities and creating a more coordinated national response to the epidemic, the Trump Administration remained largely silent on how to combat the spread of the disease for nearly 2 years, negatively affecting prevention and treatment efforts (Cahill, 2019). For example, President Trump never appointed a director of the Office of National AIDS Policy (ONAP), the White House office responsible for coordinating the federal government’s efforts to combat HIV. Similarly, over the course of 2017 and 2018, the members of the Presidential Advisory Council
on HIV/AIDS (PACHA), which provides advice to the White House on HIV policy, either quit in protest over the Trump Administration’s tepid response to HIV or were fired (PACHA was reconstituted in March 2019; Johnson, 2019).

While President Trump announced a broad strokes recommitment to combatting HIV in his 2019 State of the Union Address and reconstituted PACHA in March 2019, details of the Trump Administration’s approach are still emerging. The administration has promised to develop and update the National HIV/AIDS Strategy developed by President Obama in 2020 (DHHS, 2019a). When President Trump announced his purported focus on HIV in February 2019, he created a goal of eliminating HIV in the United States by 2030 and subsequently pledged roughly $300 million in additional funding for HIV prevention efforts in his FY 2020 budget. To reach its professed goal of a 75% reduction in infections over the next 5 years and a 90% reduction over the next 10 years, the Trump Administration intends to target resources toward so-called geographic hotspots, which have a disproportionate HIV burden, including seven states and 48 counties, along with Washington, DC, and San Juan, Puerto Rico.

While this new attention and the targeting of resources at underserved areas are welcome and are no doubt aided by devoted public servants continuing to work in the federal government, several federal and state policies undermine the Trump Administration’s professed goals. The continuation of multiple policies that stigmatize both HIV and those associated with the virus discourage people from learning their status and getting treatment, thereby allowing the disease to more easily spread from person to person. Moreover, more generalized racial, economic, and regional healthcare disparities and barriers to healthcare are impeding elimination of the virus, particularly for historically marginalized communities. Put simply, while the Trump Administration is promising additional resources for HIV, they are otherwise cutting healthcare for those in need—including populations disproportionately impacted by the HIV epidemic.

HIV Discrimination and Stigma

From the early days of the HIV epidemic in the 1980s, public health authorities—including President Reagan’s Presidential Commission on the Human Immunodeficiency Virus Epidemic, recognized that if there were not legal prohibitions on discrimination against individuals living with HIV, people would be deterred from coming forward to obtain testing and care. According to the Commission, “fear of potential discrimination ... will undermine our efforts to contain the HIV epidemic and will leave HIV-infected individuals isolated and alone” (Presidential Commission, 1988). The important recognition that discrimination impedes public health has meant that people living with HIV have been protected in a variety of contexts—including employment, public accommodations, public services, healthcare, and housing—by several federal statutes, most prominently the Americans with Disabilities Act and the Rehabilitation Act (Skinner-Thompson, 2018).

However, several important exceptions to the antidiscrimination principle persist. And, even where legal protections are in place, often the protections are underenforced.

One visible context where antidiscrimination protections for people living with HIV have not been robustly extended is military employment. While the Rehabilitation Act generally prohibits employment discrimination on the basis of disability—including HIV—by federal
government agencies, the Rehabilitation Act does not apply to military service members (though the Rehabilitation Act has been extended to civilian personnel in the armed forces), and the US military discriminates against individuals living with HIV in a couple of different ways.

First, the Department of Defense prohibits HIV-positive individuals from enlisting in the military, regardless of whether an individual is asymptomatic or otherwise healthy. Second, active-duty personnel who test positive for HIV while in the military are prevented from being appointed as an officer, are often subject to significant limitations on their deployment, and, under the Trump Administration, face increased threats of discharge because of their HIV status. Importantly, instances where individuals with HIV have been discharged or have been deemed nondeployable on the basis of their HIV status alone, without consideration of their health and fitness for duty, have come under increased legal scrutiny.

For example, in February 2019, in the decision in the case of Roe v. Shanahan (No. 1:18-cv-1565, 2019 WL 643971 [E.D. Va. Feb. 15, 2019]), a federal district court judge concluded the Air Force’s categorical policy of limiting the deployment of asymptomatic HIV-positive service members likely violates the Equal Protection clause. According to the court, categorical limitations on the ability of people living with HIV to serve are arbitrary, irrational, and ignore scientific evidence that many whose HIV is treated with antiretroviral medications are physically and mentally capable of performing all military duties required of them. Similarly, the court concluded that instances where HIV-positive service members had been discharged based solely on their HIV status, without individualized consideration of their fitness for duty, were also likely arbitrary and unlawful. (This decision was affirmed on non-constitutional grounds by the Fourth Circuit Court of Appeals in January 2020). Until each branch of the US military ends policies that treat people living with HIV in categorical, discriminatory ways, the military is perpetuating misinformation and stigma regarding HIV and the ability of those living with it to live full lives.

The nation’s blood donation policy is another context where groups associated with HIV are subject to discrimination. In 2015 and then again in April 2020, the FDA issued revised guidance governing who can donate blood and who will be deferred from donating based on the FDA’s conclusion that they pose a risk of donating HIV-infected blood (FDA, 2015). Prior to 2015, MSM were categorically and indefinitely deferred—or barred—from donating blood. Pursuant to the 2015 revisions, men were not allowed to donate if they have had sex with another man in the 12 months prior to the attempted donation. In the wake of the COVID-19 crisis and need for increased blood donations, the FDA further revised the guidance in 2020 to provide that men are not allowed to donate if they have had sex with another man in the 3 months prior to the attempted donation. While an improvement, thousands of gay and bisexual men who have sex regularly are still prevented from donating. While the policy now bears a closer relationship to the “window period” during which an HIV infection may not be detected, the policy is still irrational, fails to individually assess potential donors, and bars men from donating even if, for example, they are in a monogamous longtime relationship and both members of the partnership are seronegative (Skinner-Thompson, 2015).

In addition to stigmatizing gay and bisexual men, rather than focusing on conduct that puts someone at risk of HIV and deploying individualized assessments of each potential donor’s sexual practices (safe or not), the policy sends an inaccurate and misleading public health
message. Rather than emphasizing that anyone—regardless of gender, sexuality, race, or socioeconomic background—is at risk of contracting HIV if they engage in unprotected sex with partners of unknown HIV status, the FDA policy puts undue emphasis and attention on a group of people—gay and bisexual men—rather than risk behaviors and sexual precautions. The policy contributes to misinformation regarding who is at risk and how HIV is spread, undermining one of the key public health tools for combatting HIV—education on its transmission. Furthermore, the policy ignores the fact that the blood supply is rigorously screened and tested for HIV, meaning that the risk of contracting HIV through a blood donation is incredibly small (Cohen, Feigenbaum, & Adashi, 2014; Skinner-Thompson, 2015).

Finally, there are examples where discrimination against people living with HIV persist notwithstanding statutory legal prohibitions on that discrimination. As mentioned, federal statutes, including the Americans with Disabilities Act, prohibit discrimination against people living with HIV by places of public accommodation. This includes healthcare providers (Lambda Legal, 2010). Access to healthcare is, of course, critically important for people living with HIV. However, misinformation and stigma persist—even among healthcare providers—resulting in too many examples where providers have refused equal service to people living with HIV. In 2012, the U.S. Department of Justice (DOJ) initiated the Barrier-Free Health Care Initiative, which sought to increase enforcement of the ADA's protections for people living with disabilities—including HIV—in the healthcare setting (DOJ, 2019). While the program led to several settlements with healthcare providers who had refused to provide equal treatment to patients with HIV, it is unclear whether the program meaningfully persists under the Trump Administration.

### Criminalization of HIV

Unfortunately, the use of criminal laws to police and punish those who have engaged in activities that might have exposed others to a risk (sometimes a negligible risk) of HIV transmission continues within the United States. Over half of the states have HIV-specific criminal statutes. These statutes vary greatly, but many of them criminalize engaging in sexual conduct with another person without disclosing that one has HIV, and some criminalize sexual activities—such as oral sex—that pose a low risk of HIV transmission (Center for HIV Law & Policy [CHLP], 2019; Wolf, 2018).

States have also relied on general criminal laws—such as attempted homicide or assault laws—to prosecute people who have allegedly exposed others to HIV. Importantly, the criminal law is often applied to HIV-positive people who engage in sexual conduct even if no actual transmission of HIV occurs. Moreover, the law has been used to criminalize conduct even when the risk of transmission is very low. For example, if a person uses a condom or has an undetectable viral load, then the risk of transmission via sexual intercourse is very small. The statutes also fail to consider that now—with PrEP—all parties to a consensual sexual encounter can, if they are fortunate enough to have access to PrEP, protect themselves from HIV transmission (CHLP, 2019).

Whether pursued under general criminal law or HIV-specific statutes, the criminalization of HIV transmission has negative public health impacts. First, it discourages people from being tested. Most criminal laws have some form of knowledge requirement. If a person does not
know they are HIV positive, they may not be successfully prosecuted for potential transmission. This creates a disincentive to being tested, because if you do not know your status, you are less likely to be prosecuted for knowing transmission.

Second, when the criminal law is used to prosecute people living with HIV who engage in activities that pose a low risk of transmission (such as using a condom during sex or an individual with an undetectable viral load engaging in sex), the law perpetuates misinformation regarding how HIV is transmitted.

Third, there is little to no evidence that criminalizing sexual conduct by someone who is HIV-positive actually deters people living with HIV from engaging in sexual conduct in the first instance. That is, the criminal law does not appear deter HIV-positive individuals from having sex. As explained by the 2015 Updated National HIV/AIDS Strategy, “HIV-specific [criminal] laws do not influence the behavior of people living with HIV in those states where these laws exist.” (ONAP, 2015).

Finally, like many criminal laws, HIV criminal laws disproportionately affect people already at the margins of society and subject to overpolicing, including sex workers and people of color (Ahmed, 2016; Ahmed, Kaplan, Symington, & Kismodi, 2011).

For these reasons, the National HIV/AIDS Strategy released by the Obama Administration called for states to reexamine the use of criminal law to police potential transmission, noting that the continued “existence and enforcement of these types of laws run counter to scientific evidence about routes of HIV transmission” and may “undermine the public health goals of promoting HIV screening and treatment” because such laws make people less willing to disclose their status when they feel at greater risk of discrimination (ONAP, 2015). Nevertheless, the application of criminal law to people living with HIV persists.

Healthcare Disparities and Access to Care

In addition to combatting HIV discrimination, stigma, and criminalization—and related homophobia/transphobia and racism—more generalized healthcare disparities must be eliminated in order to effectively combat HIV. Unfortunately, certain policies are impeding greater healthcare access, including for people living with HIV or at higher risk of becoming infected (Reif, Wilson, & McAllaster, 2017).

For instance, while the ACA ensured that people living with HIV could not be denied insurance coverage for pre-existing conditions, required insurance plans to cover preventative services like HIV testing, and expanded Medicaid eligibility to adults earning up to 138% of the federal poverty level in those states that chose to expand Medicaid, the ACA's full potential for many people, including many people living with HIV, remains unfulfilled (Kates & Dawson, 2017). In addition, the ACA's future remains uncertain, as President Trump and Republican allies continue to attempt to roll back the ACA in Congress, through executive power, and in the courts.

The refusal of several states to take advantage of the ACA's expanded income-eligibility level for Medicaid (so-called “Medicaid expansion”) is a good example. Medicaid is the source of insurance coverage for the largest number of non-elderly adults living with HIV, but its reach
has been blunted because, as of the Spring 2020, 14 states have chosen not to participate in Medicaid expansion. Most of these states are in the southeast, where HIV is having a disproportionate impact. Because of these states’ refusal to expand Medicaid eligibility, more than 2 million people fall into the so-called coverage gap—meaning they make too much to qualify for Medicaid under their state’s rules, but not enough to qualify for the ACA’s marketplace insurance tax credits (Garfield, 2020). According to an analysis by the KFF, in 2015, in non-expansion states, the rate of people living with HIV who were uninsured was 19%, versus just 5% in states that had expanded Medicaid eligibility (Dawson & Kates, 2019). So, while the ACA has led to a significant overall increase in insurance coverage for people with HIV (many through Medicaid), its impact has been mitigated by the failure to expand Medicaid in every state.

In short, while President Trump’s professed commitment in 2019 to fighting HIV is a positive development, the Trump Administration’s broader attacks on the ACA and the perpetuation of stigma and discrimination toward people living with HIV, queer communities, and communities of color are undermining HIV treatment and prevention efforts.

**Conclusion**

President Obama’s National HIV/AIDS Strategy provided as its vision that “[t]he United States will become a place where new HIV infections are rare, and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity, or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.” These are important goals—goals that should drive the law and policy of the United States. While progress has been achieved toward achieving these goals, substantial barriers remain, including HIV stigma and discrimination, criminalization of HIV, homophobia, transphobia, racism, and unequal access to healthcare generally and HIV care specifically. If political capital, resources, and public attention are devoted to dismantling these barriers, then the vision of an HIV-free United States can become a reality.

**References**


Lambda Legal. (2010). *When health care isn’t caring: Lambda Legal’s survey of discrimination against LGBT people and people with HIV.*


Notes

1. Nothing in this article constitutes medical or legal advice, and before initiating any medical treatment, please consult a healthcare provider. The information and statistics contained herein were drawn primarily from sources publicly available by mid-2019, when this article was written, with some updates in spring 2020.

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