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WE THE PEOPLE

A Black Strategy to End HIV

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Introduction to a Black Strategy to End HIV

By RANIYAH COPELAND, M.P.H.
President and Chief Executive Officer
Black AIDS Institute

HIV is a disease that affects the most marginalized: Black and brown people, LGBTQ people, people living in poverty, people who don't have housing, people experiencing substance addiction, and so many others who aren't able to thrive simply because of who they are, who they love, or where they live. HIV is certainly not the only disease for which health disparities exist, but few health conditions match HIV in the degree to which it has affected those with the fewest resources to respond.

Scientifically, much has been revolutionized since the epidemic's early days. Extraordinarily effective medications have been developed to slow the progression of the disease and to prevent further HIV transmission. In the near future we are likely to have even more effective biomedical tools at our disposal—including long-acting, injectable antiretrovirals for both treatment and prevention and a plausible future of a cure and vaccine.

As optimism about available biomedical tools to fight HIV has increased, the HIV community has become more ambitious in its aspirations. Globally, in 2010 UNAIDS unveiled a vision of "getting to zero"—zero new HIV infections, zero discrimination, and zero AIDS-related deaths. That same year, the Obama administration unveiled the first National HIV/AIDS Strategy, which envisioned concerted action to reduce new infections and deaths.

These plans included important recommendations and helped unite diverse communities around a set of common goals. But, in the end, they ultimately haven't worked, as the number of new HIV cases in the U.S. has barely budged in recent years and Black people are the least likely to achieve and sustain viral suppression. While catalyzing important reforms in clinical settings, these plans failed to grapple with how HIV thrives on inhumanity, hatred and exclusion.

We cannot solely 'treat' our way out of this epidemic. It's been tried for the past 10 years and has failed. Our inability to effectively deliver these biomedical breakthroughs to those who need them most intersects with the oppressive systems and structures that the most marginalized live in. The treatments and preventive interventions we've developed are godsends for Black communities. But they have not and will not end HIV on their own. To end HIV, we must end the systems and practices that undermine, disempower, and harm Black individuals and communities. The individuals and communities who need these medications confront major obstacles for access, effective use, and receiving the support they need to prosper.

In recent years, New York State, San Francisco, and other state and local actors have put in place plans to end their HIV epidemics. And only last year, the current Administration unveiled a plan to end HIV in the United States by 2030—by allocating an additional $250 million to the FY2020 budget to intensify efforts in the 48 counties and seven states that account for most new HIV infections.

While these new initiatives are exciting and laudable, disappointment is assured if we fail yet again to address the root causes of Black America's heightened vulnerability to HIV.

Regular reports on the State of AIDS in Black America are the Black AIDS Institute's flagship publication. This is my first State of AIDS report since assuming the leadership of the Black AIDS Institute a little more than a year ago.

This *We the People* report takes up the challenge of envisioning a world without HIV, by examining the fight against HIV from an unapologetically Black perspective.

This report was developed by the Black communities and individuals impacted by HIV. We held three townhalls in the Southern U.S., surveyed Black communities, conducted over 20 informant interviews, and were guided by an advisory group of some of the most innovative Black leaders from the across the country leading efforts and organizations at the forefront of HIV and social justice issues. Their feedback and recommendations are the backbone of this report.

The reality is that the disproportionate impact of HIV in Black America cannot be separated from the long history of anti-Black racism in this country. The same forces that render Black Americans vulnerable to poverty, unemployment, limited educational opportunities, incarceration, voter suppression and housing instability are the same forces that have made HIV such a crisis in our communities. We can set all the lofty HIV goals we want, but we'll never reach them if we don't courageously tackle the dynamics that increase Black people's risk for HIV and reduce our ability to benefit from biomedical breakthroughs.

Over the next year BAI will be working with our Black Treatment Advocate Networks (BTAN) and other partners across the country to host more than 10 townhalls to develop jurisdictional recommendations to end HIV within their Black communities. BAI will then support concerted efforts to move key recommendations in local communities and states to support the uptake of biomedical tools for Black people. *We The People* is more than a theoretical document, it is the strategy we will use to make meaningful progress towards ending HIV in Black America.

As a mother of two Black boys, I know in the deepest part of my being that the well-being of Black people inevitably depends on true freedom—our freedom to choose our own destiny, to have an equal chance to succeed, freedom from discrimination and exclusion and freedom to live within our full dignity as humans. These are the values I was raised with and guide my life's work. It's why I'm so deeply committed to our community's health and wellness, and why I am so deeply honored to lead the Black AIDS Institute.

If we truly hope to end HIV, we'll need to approach this challenge in innovative and radical new ways. As Black Americans, we must own this fight and articulate and drive new ways of doing business. That is the vision set forth in *We the People*—a blueprint for ending HIV in our communities.

Raniyah M. Copeland

We The People

When the country's founders began the Constitution with the words "We the People," they intended to signal the emergence of a new way of organizing human affairs. In the place of government by and for the few—the default option throughout most of human history—the words "We the People" indicated that in the future the voice of the people would be paramount.

While the phrase "We the People" continues to inspire efforts to form a more perfect union, the gap between the vision of people-empowered government and the reality of life in the United States was gaping from the country's very beginning.

And it persists today.

Congreſs of the United States

In Congress. July 4, 1776.

The unanimous Declaration of the thirteen united States of America,

We the People


RACE MIXING IS COMMUNISM
STOP THE RACE MIXING MARCH OF THE ANTI-CHRIST
RACE MIXING IS COMMUNISM

Only property-owning white males were allowed to vote when the Constitution was ratified, effectively excluding the majority of people from the country's democratic system. Even as the Declaration of Independence declared that "all men are created equal," the country's first census in 1790 disclosed that 700,000 Black people were living in slavery, with slaves present in 12 of the 13 original states.[1]

And the Constitution itself expressly denied the full humanity of Black people, decreeing that enslaved Black people would count as three-fifths of a human being for purposes of apportioning seats in the House of Representatives.

The Enduring Legacy of Anti-Black Racism

In the quest to build a more inclusive union, much has changed since the Constitution was put in place. A brutal civil war resulted in the abolition of slavery; due to courageous activism by Black people from all walks of life, landmark civil rights legislation was enacted in the 1960s, including laws to prohibit voting restrictions imposed in the Jim Crow South; and in 2008 America elected its first Black president.

Yet the stain of anti-Black racism apparent at the country's founding continues to endure, affecting and distorting virtually every element of American life.

Economics

Today, the wealth of the median Black household is roughly 5% of the wealth of the median white household[2]—the product of decades of redlining, evictions and disproportionate, unrecovered losses from the Great Recession. Black Americans are more than twice as likely to live in poverty as white Americans.[3] Even in the midst of record low unemployment, Black people are roughly twice as likely as whites to be out of a job.[4]

Health and Well-being

In 2017, life expectancy was 3.3 years shorter for Black Americans than for whites and 5.5 years shorter compared to Latinx people.[5] Infants born to Black women are more than twice as likely to die as those born to white women.[6] Black people are 23% more likely than white people to die of heart disease[7], 12% more likely to die of cancer[8], and roughly twice as likely to die of diabetes.[9]

Non-elderly Black people in 2018 were 30% more likely than non-elderly white people to report lacking a usual source of medical care (although they were 23% more likely to have a usual source of care than non-elderly Latinx people).[10]

Personal liberty

In a country where the frequency of incarceration is unmatched worldwide, Black Americans are incarcerated at five times the rate of white Americans (six times among males). [11] [12] Even though Black and white people report similar rates of drug use, Black people are incarcerated on drug-related charges at a rate six times greater than white people.[11] [12] Although Black people make up only 14% of youth under age 18, they represent 43% of boys and 34% of girls confined in juvenile facilities.[13]

Enfranchisement

In response to the election of the country's first Black president, and also in the aftermath of a 2013 Supreme Court decision dismantling key provisions of the Voting Rights Act, numerous states across the country, but especially in the

South, have erected multiple barriers to the ability of Black people and other people of color to exercise their constitutional right to vote.[14] These impediments to the right of Black people to vote are hardly accidental, with one federal appeals court finding that North Carolina's voter ID law "target[ed] African Americans with almost surgical precision."[15]

HIV and Black America

The HIV epidemic vividly reflects the persistent and comprehensive disadvantages and disenfranchisement experienced by Black America. Although Black people account for a mere 13% of the U.S. population, they comprised 43% of new HIV diagnoses nationally in 2017, 43% of AIDS-related deaths, and 42% of all people in the U.S. living with HIV.[18] Black youth (ages 13-29 years) in 2010-2014 were 10.5 times more likely to be diagnosed with HIV than their young white peers.[19] As the Black AIDS Institute documented in its landmark report, *Left Behind,* were Black America a country in its own right, its HIV epidemic would rank among the world's largest, surpassing in severity many national epidemics in sub-Saharan Africa.[20]

The impact of HIV on Black same-gender loving men remains profound. Based on current trends, the Centers for Disease Control and Prevention (CDC) projects that an astonishing one in every two Black gay men will acquire HIV during their lifetime.[21] Unfortunately, there is little evidence of progress in turning the tide against HIV among Black same-gender loving men. Among young men who have sex with men (ages 13-29), Black men accounted for 49% of new HIV diagnoses in 2008-2016.[22] Among Black gay men ages 25-34, new HIV diagnoses increased by 40% from 2010 to 2016.[19]

HIV is having a similarly marked impact on Black trans people. Nationally, 44% of Black trans women are living with HIV—an HIV prevalence that is more than six times higher than among white trans women.[23] Around half of all trans people diagnosed with HIV live in the South.[24] The longstanding, erroneous tendency of public health authorities to treat the trans population as a subset of men who have sex with men has undermined efforts to mount an effective response to address the HIV prevention and treatment needs of trans people.

The epidemic's disproportionate impact on Black communities is apparent across the nation, but HIV among Black communities in the South is nothing short of a crisis. Home to a majority of Black Americans, the South is also the center of the HIV emergency in Black America. Accounting for 38% of the U.S. population, the South represents 51% of new HIV diagnoses in the U.S.[25] Due to late HIV diagnosis and widespread barriers to healthcare access and utilization in the region, HIV-related mortality in the some Southern states is three times higher than among people living in states outside the region.[25]

As stark as the extraordinary racial disparities in the U.S. HIV epidemic is the fact that the epidemic's marked impact in Black communities has often elicited so little response—from policy-makers, public health officials and even Black America itself. Throughout much of the epidemic's first two decades, HIV was regarded primarily as a disease of white gay men.[26] Yet the epidemic's disproportionate impact in Black communities was thoroughly documented from the very beginning of the epidemic itself. During the epidemic's first two years (1981-1983), Black people made up 26% of all reported AIDS cases, at a time when Black people represented less than 12% of the U.S. population.[27] As early as 1994, HIV sero-surveys found that young Black gay men were acquiring HIV at rates several times higher than among young white gay men[28].

Every time a major scientific advance in the fight against HIV has occurred, Black

Slavery's impact on every facet of American life: The 1619 Project

In August 2019, the country's most influential daily newspaper, *The New York Times,* marked the 400th anniversary of the beginning of slavery by launching the 1619 Project. "No aspect of the country that would be formed here has been untouched by the 250 years of slavery that followed," the *Times* declared.

"Out of slavery—and the anti-black racism it required—grew nearly everything that has truly made America exceptional: its economic might, its industrial power, its electoral system, its diet and popular music, the inequities of its public health and education, its astonishing penchant for violence, its income inequality, the example it sets for the world as a land of freedom and equality, its slang, its legal system and the endemic racial fears and hatreds that continue to plague it to this day. The seeds of all that were planted long before our official birth date, in 1776, when the men known as our founders formally declared independence from Britain."[16]

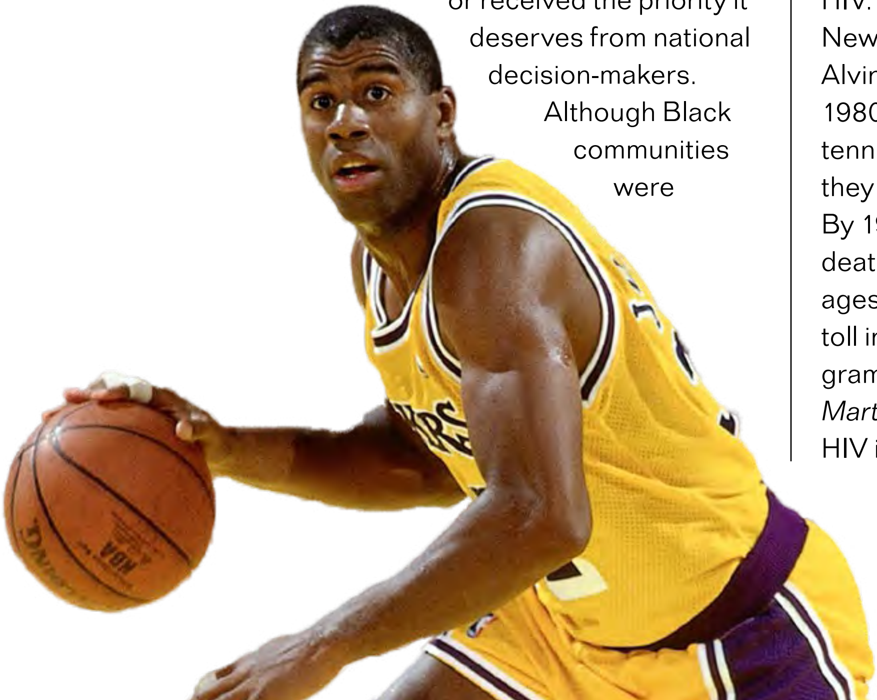
To mark the project's beginning, a special issue of *The New York Times Magazine* was devoted to the project. Essays by leading historians, journalists, authors and activists examined diverse facets of American life—policing, economic life, healthcare, incarceration, the country's electoral system—to explore the continuing effects of slavery. Demand for the issue was greater than for any other single issue in the magazine's history. The project is now being translated into two series of books—one for adults, and another for children.

Linda Villarosa, a New York-based journalist, was the author of one of the original Project 1619 essays. Villarosa's essay examined how misconceptions about perceived physiological differences between Black and white people have influenced healthcare delivery and how some of these pernicious falsehoods (such as the lie that Black people are less likely to experience pain than white people) continue to affect clinical decision-making. Villarosa is building on her essay to produce one of the books that will be published as part of Project 1619.

Villarosa has written extensively about HIV, including participating in delegations of journalist that the Black AIDS Institute has pulled together to attend international AIDS conferences and scientific meetings. In 2017, *The New York Times Magazine* published a landmark story by Villarosa on "America's Hidden HIV Epidemic."[17] The article focused on the acute and growing HIV epidemic among young, poor Black gay men in rural Mississippi, asking "Why do America's Black gay and bisexual men have a higher HIV rate than any country in the world?"[17]

40 Years of Struggle: The History of the Response to HIV in Black America

Nearly four decades separate the initial recognition of AIDS and the launch of *We the People.* Much about HIV has changed in those years, but one tragic reality has persisted. Across the history of the epidemic, Black communities in the U.S. have experienced a disproportionate burden of HIV. And while the history of HIV in Black America includes important examples of courageous leadership, the fight against HIV in Black America has never been fully and enthusiastically owned by the whole of Black America itself or received the priority it deserves from national decision-makers. Although Black communities were disproportionately affected by HIV from the epidemic's beginning, the large AIDS service organizations established in the early 1980s in the cities where AIDS cases were concentrated were primarily grounded in white gay communities. In recognition of the need for a genuine community-centered response to the rapidly expanding health emergency in Black communities, the first Black-led AIDS organizations emerged in the 1980s, including the National Black Leadership Commission on AIDS, Balm in Gilead, National Task Force on HIV Prevention, Minority AIDS Project, Bebashi, SisterLove and others. Black HIV activism also emerged in the 1980s, including the first-ever conference on AIDS among Black people and a protest at the American Public Health Association's first session on AIDS, which included no people of color. Much of the early Black HIV activism was informed by the renaissance in Black gay culture that occurred in the 1980s. Spurred in part by Balm in Gilead, the late 1980s witnessed the stirrings of an initial response to HIV by Black faith-based groups, as a number of churches eventually moved to create local AIDS ministries.



Yet, even as an early Black response to HIV was born, the epidemic's impact in Black communities acutely worsened. New AIDS cases among Black women rapidly escalated in the 1980s and 1990s, and city-specific HIV surveys found that Black gay men were several times more likely than white gay men to acquire HIV. Leading Black figures, such as ABC World News anchor Max Robinson and dance legend Alvin Ailey, died of AIDS-related causes in the 1980s, and basketball star Magic Johnson and tennis great Arthur Ashe publicly disclosed that they were living with HIV in the early 1990s. By 1993, HIV had become the leading cause of death among Black men and women between ages 25 and 44. As HIV was exacting such a toll in Black communities, entertainment programming catering to Black audiences, such as *Martin* and *A Different World,* took account of HIV in their storylines.

Black political leaders increasingly priori-

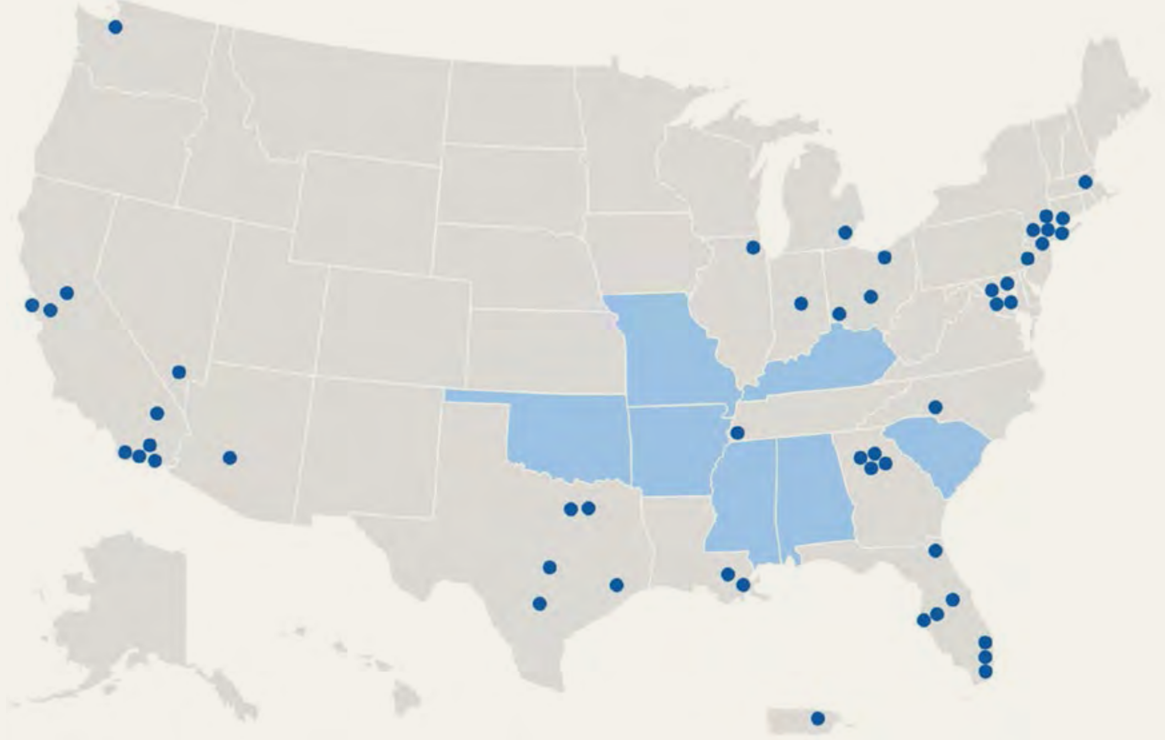
tized HIV in the epidemic's second and third decades. Members of the Congressional Black Caucus spearheaded creation of the Minority AIDS Initiative, which allocated focused funding to fight HIV in communities of color. A delegation of Black political leaders attended the 2006 International AIDS Conference in Toronto, where they demanded substantially greater attention and resources to address the HIV crisis in Black communities.

The Black AIDS Institute was launched in 1999, with the goal of stopping the epidemic in Black America. Its first effort was to convene a diverse group of Black leaders and stakeholders to assemble the *Nia Plan,* which provided a roadmap for mobilizing Black America to respond effectively to HIV. Consistent with the recommendations in the *Nia Plan,* the Black AIDS Institute assisted a dozen leading national Black organizations (such as NAACP, Rainbow Push and the Urban League) to create their first organizational HIV strategic plans. Following intensive advocacy by the Black AIDS Institute, CDC established the Act Against AIDS Initiative, which funneled resources to national Black institutions to allow implementation of these organizational HIV strategic plans.

The last decade has seen both important advances in the fight against HIV and continuing evidence that many Black communities are being left behind. The Obama Administration unveiled the country's first national HIV strategy, the Affordable Care Act was signed into law, CDC focused substantial new funding on HIV prevention services for gay men of color, and biomedical advances increased optimism regarding the possibility of ending the HIV epidemic. But at the same time, CDC reported that a Black gay men faces 50% odds of acquiring HIV during his lifetime and that Black people living with HIV experience consistently poorer HIV treatment outcomes than other HIV-positive people.

Although news coverage of HIV in Black America has declined in the mainstream media since its high water mark at Magic Johnson's coming-out, HIV has been featured in plot lines of a number of major Hollywood television shows, including *Pose, How to Get Away with Murder* and *Empire.* But the prominence of HIV in Black community discourse remains far below what is needed. At a time when the tools exist to bring to an end an epidemic that has visited such devastation on Black communities, HIV warrants the deep and sustained engagement of Black people of all walks of life.

Jurisdictions Prioritized in Ending the HIV Epidemic: A Plan for America



Americans have often been left behind. In the early years of Highly Active Antiretroviral Therapy (HAART) beginning in the mid-1990s, studies consistently found that Black people living with HIV were notably less likely than HIV-positive white people to receive life-saving HIV treatment.[29] Today, roughly 25 years after the advent of the HIV treatment revolution, critical disparities persist. In 2017, Black people receiving antiretroviral therapy (ART) were 17% less likely than white antiretroviral therapy recipients to achieve viral suppression.[30]

In a number of cities, such as New York and San Francisco, the combination of improved HIV treatment access and outcomes and rapid uptake of pre-exposure antiretroviral prophylaxis (PrEP) is helping drive down new HIV infections. Here, too, however, Black communities are too often failing to benefit. While 42.1% of white people needing PrEP in 2017 were receiving it, only 5.9% of Black people who were eligible for PrEP were taking it—a seven-fold difference in PrEP coverage.[30]

The broader economic and social disadvantages experienced by Black Americans are integrally linked with the disproportionate impact of HIV in Black communities. Compared to HIV-positive MSM as a whole, Black MSM living with HIV are six times as likely to have low income, three times as likely to have low educational attainment, and also notably more likely to be unemployed or to have ever been incarcerated.[31]

The Quest to End HIV in the United States

Since its founding in 1999, the Black AIDS Institute has been dedicated to a single, overarching goal—ending the HIV epidemic in Black communities. In its first decade of existence, the Institute focused on increasing awareness of the HIV crisis in Black America and mobilizing leading Black institutions to respond more vigorously and effectively to the epidemic. In its definitive history of the Black response to HIV in the U.S., the Black AIDS Institute declared that "30 years is enuf!"[32]

The following year, spurred by new research findings that antiretroviral therapy reduces by 96% or more the risk of HIV transmission[33], the Black AIDS Institute released a strategy for ending the HIV epidemic in Black communities, prioritizing early knowledge of HIV status, scale-up of HIV treatment, retention in care, and sustained viral suppression.[34] Since publication of its 2012 strategy, additional evidence of the powerful prevention benefits of PrEP has further buttressed hopes that the epidemic can be ended.[35]

Growing hopes for ending the HIV epidemic have galvanized action at the state and local level. Black organizations and stakeholders have played key roles in putting in place plans to end the HIV epidemic in many parts of the U.S., including New York State, Houston, Washington D.C. and Fulton County GA.[36] [37] [38] [39]

In 2019, the Trump administration unveiled *Ending the HIV Epidemic: A Plan for America.*[40] With the goal of reducing new HIV infections by 75% by 2025 and by 90% by 2030, the strategy has four pillars: (1) Diagnose all individuals with HIV as early as possible; (2) Treat people with HIV rapidly and effectively to reach sustained viral suppression; (3) Prevent new transmission by using proven interventions, including PrEP and syringe services programs; and (4) Respond quickly to potential HIV outbreaks to get needed prevention and treatment services to people who need them. The national initiative calls for intensified efforts in 48 counties, Washington DC., San Juan, Puerto Rico, and seven states with substantial rural epidemics (primarily in the South).

A Black Strategy to End HIV in America

Although the federal government's new initiative for ending the HIV epidemic is a welcome development, we have far to go to declare an end to HIV in the United States. While certain cities have seen encouraging declines in new HIV diagnoses, the country as a whole has made only minimal progress in reducing the number of new HIV diagnoses.[41]

Failure to effectively address the factors that increase HIV vulnerability in Black communities and the impediments to accelerated service uptake is a key reason why progress in the HIV fight remains so slow. In this regard, the federal plan is concerning. While the plan rightly prioritizes greater geographic focus in the national response, it does not openly grapple with the social and structural factors that contribute to racial and ethnic disparities in HIV outcomes.

As every advance in the HIV response has often been accompanied by an increase in HIV disparities, it is apparent that business as usual will not enable us to end HIV. And in an epidemic that most heavily affects Black communities, it is equally plain the national epidemic as a whole cannot be ended if it is not ended in Black America.

One of the most promising features of *Ending the HIV Epidemic: A Plan for America* (also known as EHE) is its emphasis on doing things differently and encouraging innovation in the HIV response. *We the People: A Black Strategy to End HIV in America* has been developed in the spirit of doing things differently. While the roles of biomedical tools for ending HIV are well understood, we will only obtain the results we seek from these tools if we operate in radically new ways. We must straightforwardly acknowledge the degree to which HIV disparities are grounded in racism and in anti-Black systems and institutions, and we must find innovative ways to meet the needs of Black communities, addressing each individual in their fullness and grounding service approaches in the lived reality of Black people. HIV in America is a racial and social justice issue, and addressing HIV as if it were solely a health issue is a sure recipe for failure.

This strategy is named *We the People* for several reasons. At the most basic, it aims to embrace and fully realize the inclusive vision rather than the exclusionary reality of our country's founding, by promoting equitable health and well-being in ways that recognize the dignity and worth of every person. *We the People* also emphasizes the centrality of communities in advancing health and well-being and the right of communities to lead and shape efforts to respond to the problems they face. Toward this end, *We the People* prioritizes the empowerment of Black communities.

Consistent with the name of the strategy, the Institute has pursued a people-centered approach to developing *We the People: A Black Strategy to End HIV in America.* Through extensive outreach and consultation, the Institute has sought the input of Black communities and stakeholders regarding what needs to change in order to end HIV in Black America. The Institute conducted more than 20 interviews with key informants from across the country, undertook surveys of HIV workers, solicited recommendations from the 14 chapters of the Black Treatment Advocates Network (BTAN), conducted town hall meetings in three Southern cities (Houston, Montgomery and Natchez) and hosted a community forum at the U.S. Conference on AIDS. In December 2019, 20 diverse stakeholders and experts gathered in Los Angeles to assist the Institute in finalizing the plan's recommendations and strategic directions.

The We the People strategy, outlined in the remainder of this report, rests on four pillars:

1 Dismantle anti-Black practices, systems and institutions that endanger the health and well-being of Black people and undermine an effective, equitable response to HIV in Black America.

2 Provide resources and services that address the fullness, richness, potential and expertise of Black people and mitigate social and structural factors that worsen health outcomes in Black communities.

3 Ensure universal access to and robust utilization of high-quality, comprehensive, affordable and culturally- and gender-affirming healthcare to enable Black people to live healthy lives in our full dignity.

4 Build the capacity and motivation of Black communities to be the change agents for ending HIV.

Under each pillar, the strategy includes specific recommendations. The Institute has established indicators and milestones for its recommendations as well as for overall

outcomes. The Black AIDS Institute will issue regular reports to enable transparent assessment of progress.

We the People is a strategy for America as a whole—and specifically for Black America. The Black AIDS Institute lacks the capacity to implement this strategy on its own, and it has no desire to, as the purpose of this strategy is to spur investment and engagement across the breadth of Black America. That being said, the Black AIDS Institute is orienting its work around the action blueprint outlined here, with the aim of accelerating and supporting the work of diverse partners and stakeholders. In particular, the Black AIDS Institute's work with its 14 BTAN chapters and 12 affiliates—most of them located in priority EHE jurisdictions—will use *We the People* as a framework for action at the local and state levels.

In addition to outlining an action plan to end HIV, this report also includes profiles of Black excellence, highlighting how Black activists and leaders are pioneering new, effective, intersectional ways to respond to HIV in their communities. These profiles are more than mere side notes, but instead reflect to the very core of *We the People.* Only if Black communities are empowered, supported and effectively resourced will it be possible to end this national epidemic. The profiles of excellence speak to the extraordinary potential in Black communities all across the country, which needs to be unleashed to lead the way toward ultimate victory in our long struggle against HIV.

Celebrating, Healing and Transforming Lives to Resist Transphobia

Joy, pain, victory and loss are invariably part of life. In navigating these contradictions, families can be our most important foundation of love, support and inspiration. But for Black and brown trans and queer people, families can also perpetuate violence, thereby causing trauma and rejection for far too many people. Toni-Michelle Williams used her own experiences with her family to embark on a life of healing, empowerment and leadership development—for herself, her family and for the broader Black trans community in Atlanta.

Williams is a performance artist and the executive director of the Solutions Not Punishment Collaborative, Inc. (SNaPCo). SNaPCo is a Black trans- and queer-led organization that focuses on developing the leadership of Atlanta's Black trans and queer community through transformative campaigns. She is a celebrated community organizer on prison abolition/prison reform issues, and the criminalization of poverty amongst Black trans people, sex workers, people living with HIV, and emerging leaders within those communities. In addition, she is an innovator in Black trans feminism and peer-led, community-based leadership development for Black transgender women. Her mission is to transform the lives of Black children across the diaspora by challenging Black families to shift the ways in which they care for and are present with their children and with each other. She is tackling this mission with a course entitled, "Transforming Transphobia."

Having grown up in Atlanta, Williams recalled, "I didn't get kicked out of the house because I was perceived as gay, trans or queer," she said. "I was kicked out because my mother could not identify or articulate her triggers. The rage and trauma that she embodied impacted our ability to be fully present with one another, and at times still does. For me I lived in fear of her actions and in resentment of her inability to just listen to me, believe me and ultimately to trust me. I do believe that during that time, she was figuring out her worth as a young Black woman, a single mother, and student.

"People may use their perception and fear of queerness or transness as an excuse for violent and manipulative behavior, like isolation, rejection, physical and sexual violence. Being complacent with transphobia and homophobia in our households only continues to affirm the cisgender heterosexual person's lack of empathy and action around the harassment and murders of Black and brown trans women. Not challenging and committing to transform transphobia within our families only breeds violence against ALL genders.

"I don't believe that transphobia will ever end, will racism? I do believe, though, that people—our hearts, minds, and language—can be transformed."

Having experienced physical and sexual violence by her family and community during childhood, it would have been understandable for Williams to remain in a place of bitterness. But she chose a different path—one of grace and self-love.

"Despite the abuse that I have experienced by my mother, she has always been supportive of my endeavors," Williams said. "These are the contradictions. She showed up to every stage play and sent me to auditions and even today, shows up to award ceremonies and actions/rallies in support of Black trans Lives.

"[My relationship with my family] today is a result of a commitment that I made five years ago about creating new memories with my family, especially with all of my babies and youth. I began modeling the quality of relationships that I deserved and desired for myself, serving them patience, grace, and truth without explanation or apology. Especially when their toxicity began to harvest lies that would continue hold us back from each other."

That commitment on the part of Williams, over time, resulted in a sea change within her own given family. "It was not an easy five years, though. But now, my entire family is accepting and at ease with my transition, Christmas's, ThanksTaking, and Easter Sunday's be litty.

"A part of transformation is an active commitment toward curiosity. They support SNaPCo events, Pride marches, and rallies that intersect with trans issues, like reproductive and immigration rights.

"Of course, there is so much more to do and learn. My grandmother misgenders all the time, girl. But after seven years she catches herself and apologizes. I know that she loves and adores me. She tells me that I am beautiful whenever I walk through the door, and with every chuckle she reminds me that no one else makes her laugh as hard as I do. She cusses me out and pinches my ears when my truth sharing feels too heavy to receive. She knows that it is not disrespect. I am grateful for her. As a trans women, that is all I can ask for from a 72-year-old Black woman, raised and bred in the South."

And Williams now has a better relationship with her mother. "When I began my journey of self- love, and transitioning I had no idea how to get to the other side of that kind of pain," she said. "I just knew that I would make it, and I knew how I wanted to feel once I did. Our families must transition too. Give them space to grieve their perception of who you were. Be patient as they move through their shame for not seeing or believing you in your truth."

After being a program of the Racial Justice Action Center for seven years, SNaPCo became an independent, not-for-profit agency at the beginning of 2020. Through their advocacy and policy analysis, SNaPCo has "shifted the culture in Atlanta" and helped start "a national conversation around violence against trans women at the hands of the police." Moving forward, a key focus of SNaPCo will be on working to encourage the Atlanta City Council to pass protections for trans and queer people and to reduce the toll of the criminal justice system on trans sex workers, by minimizing arrests for solicitation, idling and loitering. Williams piloted the "Transforming Transphobia" course in 2019 with about 50 AFROPUNK staff, including Co-Founders Jocelyn Cooper and Matthew Morgan, and she hopes to share this course with others around the world. Williams' work includes organizing Atlanta's queer and trans communities to create and implement the Atlanta/Fulton County Pre-Arrest Diversion Initiative, leading the effort to a reduce penalties for marijuana possession, and collaborating with sister project, Women on the Rise in the closure of the Atlanta City Detention Center in the summer of 2019.

Black AIDS Institute Launches National Plan to End HIV

The Black AIDS Institute (BAI) is coming to Natchez, MS to rollout a plan to end the HIV epidemic in America. In Trump's February State of the Union address he announced an initiative to end HIV in the U.S. in 10 years. His plan, entitled Ending the HIV Epidemic: A Plan for America (ETE) has since committed over $250 million in FY2020 to be directed towards 47 jurisdictions and 7 states to implement the initiative. Mississippi is one of the 7 states in the first phase of the initiative. BAI has developed a plan to ensure that Black communities are not left behind, entitled We the People: A Black Plan to End HIV in America. The Administration's plan, does not address the drivers of HIV that fuel the disproportionate impact HIV has had in Black communities. BAI's community led plan will provide a foundation for intervening around social determinants of health that directly marginalize Black people and proliferate HIV in America. We the People: A Black Plan to End HIV in America is a unique and unapologetically Black initiative that is designed to transform the nature of HIV testing, treatment, and advocacy in Black communities across the U.S. and ultimately end HIV by those most impacted by it.

Speakers will include Natchez Mayor Darryl Grennell, President of the Southern Christian Leadership Foundation Bernice Frazier, Mississippi State AIDS Director Kendra Johnson, BAI President and CEO Raniyah Copeland, and many more.

When:
October 10, 2019
5:30 - 7:30 pm
Where:
Alcorn State College of Nursing Auditorium
15 Campus Drive
Natchez MS 39120

Register at https://wethepeoplenatchez.eventbrite.com

African

PILLAR 1

Dismantle anti-Black practices, systems and institutions that endanger the health and well-being of Black people and undermine an effective, equitable response to HIV in Black America

The roots of Black America's disproportionate HIV burden are not a mystery. The oppression, disenfranchisement and marginalization of Black people largely explain why Black Americans in 2013-2017 were more than eight times as likely to be diagnosed with HIV as white Americans.[42] The subordination of Black people extends across multiple domains—in housing, employment, criminal justice, sexual and reproductive rights, sexual expression, gender identity, and voting.[1]

While biomedical tools have enabled some advances in the fight against HIV in Black America, we will never end the epidemic without tackling the sources of Black people's vulnerability to HIV. Efforts to expand access to and utilization of breakthrough biomedical tools must be complemented by an equally robust commitment to reforming and, where needed, dismantling practices, systems and institutions that contribute to Black America's health disparities.

Develop and effectively resource local and national anti-racism and social justice coalitions that situate HIV within a broader context of human rights

HIV must be addressed not merely as a public health issue but as a racial and social justice issue. Some movement in this direction—such as the establishment of the HIV Racial Justice Now coalition—can be seen at the national level, although these efforts remain under-resourced and inadequately mainstreamed across the HIV

1, Anti-Blackness is defined by the Council for Democratizing Education as a two-part phenomenon that "voids Blackness of value while systematically marginalizing Black people and their issues." Anti-Blackness is manifested in anti-Black racism, which refers to the "unique discrimination, violence and harms imposed on and impacting Black people specifically." (The Movement for Black People's Lives, Glossary, https://policy.m4bl.org/glossary/, accessed on January 11, 2020.)

Using a Racial Justice Approach to Fight HIV

Venita Ray, who has lived with HIV for 16 years, sees a lot of "disconnects" when she surveys the HIV landscape. Although the HIV epidemic most heavily affects Black communities, the most important decision-makers on HIV are seldom Black themselves. "The folks in decision-making on HIV are not reflective of the people most impacted," she observed, "so the responses they give are often superficial and based on a negative, stereotypical image of the people most affected."

In addition, Ray noted, funders don't always allocate resources to the grassroots groups with the greatest organic connection to their communities. And many of the service organizations that receive HIV funding lack the capacity to provide culturally appropriate and humble services to Black people living with or affected by HIV.

"AIDS Inc. has just become a machine of its own that doesn't always have a connection with people living with HIV," Ray said. "It is a self-fulfilling operation versus a real on-the-ground effort. We need to stop pretending that permanent volunteerism is an effective and sustainable way to reach the communities most affected, and we need to stop using Ryan White planning councils and HIV prevention planning groups as stand-ins for community engagement."

In 2017, the organization Ray leads, Positive Women's Network, joined with the Counter Narrative Project to obtain a Ford Foundation grant focused on infusing a racial justice framework into the domestic HIV movement. Counter Narrative is also Black-led, founded and currently led by a former fellow of the Black AIDS Institute's African-American HIV University.

"The real issue is understanding that most of what we are talking about when we talk about HIV is the shaming and blaming of Black and brown folks for acquiring HIV," Ray said.

An initial convening of people of color leaders in New York gave birth to HIV Racial Justice Now, a coalition of people of color devoted to building a racially just and strategic domestic HIV movement. The coalition adopted a Declaration of Liberation that committed to "develop[] and nurtur[e] a leadership body in

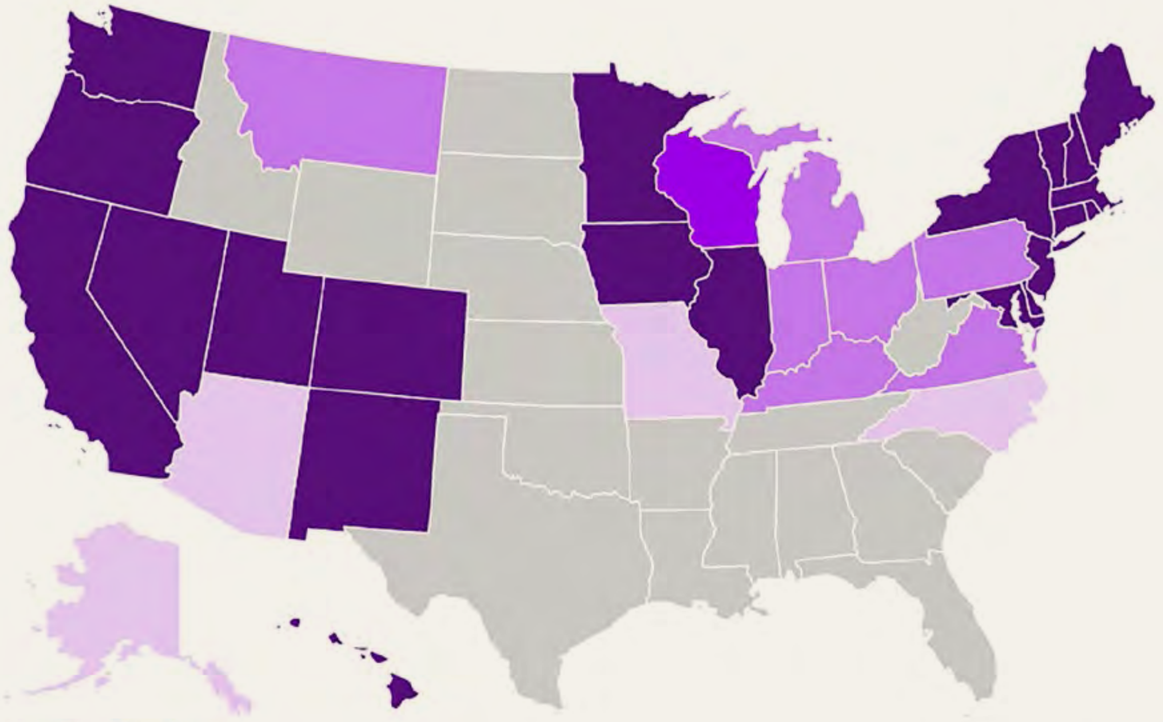
the HIV movement that reflects [the variation of experience in Black and brown communities], uplifting Black and brown leadership and centering communities that are most impacted by the epidemic." The Declaration calls for integrating racial justice into HIV organizations and political strategies, ensuring accountability to the communities most affected by HIV, ensuring equitable allocation of human, material and financial resources, and transforming and, where necessary, dismantling institutions that "uphold white supremacy and compromise the wellbeing of communities of color."

"It is our contention that any struggle for justice or equity in HIV must become a racial justice movement," the Declaration states. "Health inequities faced by Black, brown and indigenous people, historically and in our present moment, are structured by historical and present-day racism. If we claim to be leaders in HIV prevention, access to care, or human rights, it is our responsibility to pressure institutions, from the clinic to the government, from funders to the courtroom, to act in the service of racial equity and justice, and to divest from the interests of white supremacy."

Ray said that early conversations between the coalition and HIV funders and organizations had encountered initial resistance, but that people in the HIV field are increasingly receptive to the coalition's message. "Our purpose is not to point a finger of blame, but simply to expand the HIV conversation to help people understand that racial injustice is a driver of the epidemic," Ray emphasized. "You need the people who are most impacted in decision-making roles."

HIV programs, Ray said, need to extend beyond biomedical tools such as PrEP and treatment as prevention and tackle broader issues of intergenerational trauma and racial injustice. "We haven't seen a shift at the institutional level yet, but we are getting some traction [with HIV funders] with our message."

Status of State Laws Prohibiting Employment Discrimination Based on Sexual Orientation and Gender Identity



Updated June 07, 2019

The Federal Equal Employment Opportunity Commission is currently accepting complaints of sexual orientation and gender identity discrimination in employment based on Title VII's prohibition against sex discrimination.

*State courts, commissions, agencies, or attorney general have interpreted the existing law to include some protection against discrimination against transgender individuals in Florida.

*North Carolina's executive order enumerates sexual orientation and gender identity. However, this order has a bathroom carve out for transgender employees making the executive order not fully-inclusive.

- 🟪 **Prohibit discrimination based on sexual orientation and gender identity** (21 states & D.C.): California, Colorado, Connecticut, Delaware, District of Columbia, Hawaii, Illinois, Iowa, Maine, Maryland, Massachusetts, Minnesota, Nevada, New Hampshire, New Jersey, New Mexico, New York, Oregon, Rhode Island, Utah, Vermont, Washington
- 🟪 **Prohibit discrimination based on sexual orientation only** (1 state): Wisconsin
- 🟪 **Prohibit discrimination against public employees based on sexual orientation and gender identity** (7 states): Indiana, Kentucky, Michigan, Montana, Ohio, Pennsylvania, Virginia
- 🟪 **Prohibit discrimination against public employees based on sexual orientation only** (4 states): Alaska, Arizona, Missouri, North Carolina

Source: Human Rights Campaign, https://www.hrc.org/state-maps/employment

response. A similar approach is required at the state and local level, in order to help state and local decision-makers transcend traditional health siloes and adopt more comprehensive, multi-dimensional strategies to dismantle racist policies, institutions and structural norms and thereby improve health outcomes and achieve health equity.

One example of a multi-disciplinary coalition is the Greensboro Health Disparities Collaborative, which works locally in North Carolina to better understand and address health disparities, using an intersectional lens that links racism with inequitable health outcomes.[43] The 14 chapters and 12 affiliates of the Institute's flagship Black Treatment Advocates Network (BTAN), most of which operate in priority EHE jurisdictions, also offer a unique vehicle for assembling broad, multi-sectoral coalitions that situate the HIV fight within the broader push for racial and social justice.

Mobilize Black communities, allies and elected officials to reform laws and policies that impede the fight against HIV in Black America

Action is needed at the federal, state and local levels to remove obstacles to an effective HIV response.

Enact laws that recognize the diversity of gender identity, prohibit discrimination based on sexual orientation, and implement gender-affirming laws, policies and practices

Stigma undermines the HIV response by worsening the physical and mental well-being of LGBTQ people, deterring LGBTQ people from seeking needed health services, and diminishing the quality and effectiveness of health services.[44] American laws and policies often reflect and reinforce stigmatizing attitudes and discriminatory practices toward LGBTQ people. Less than half of LGBTQ Americans live in jurisdictions that prohibit job or housing discrimination on the basis of sexual orientation or gender identity.[45] For the HIV response in Black America, it is especially noteworthy that no state in the South has such anti-discrimination laws in place.[45] All but two Southern states have laws or constitutional provisions in place that permit people to seek exemptions from anti-discrimination laws based on their religious beliefs.[46] In addition to causing deep harm to people's livelihoods and happiness, anti-LGBTQ discrimination also denies the very dignity of LGBTQ lives, making it even more challenging to respond effectively to the heightened threat of HIV among Black LGBTQ people.

These laws help create a climate that effectively sanctions discrimination and abuse toward LGBTQ people. Compared to cisgender high school students, trans students are five times as likely to feel unsafe at school, 2.3 as likely to be bullied, and more than six times as likely to attempt suicide.[47]

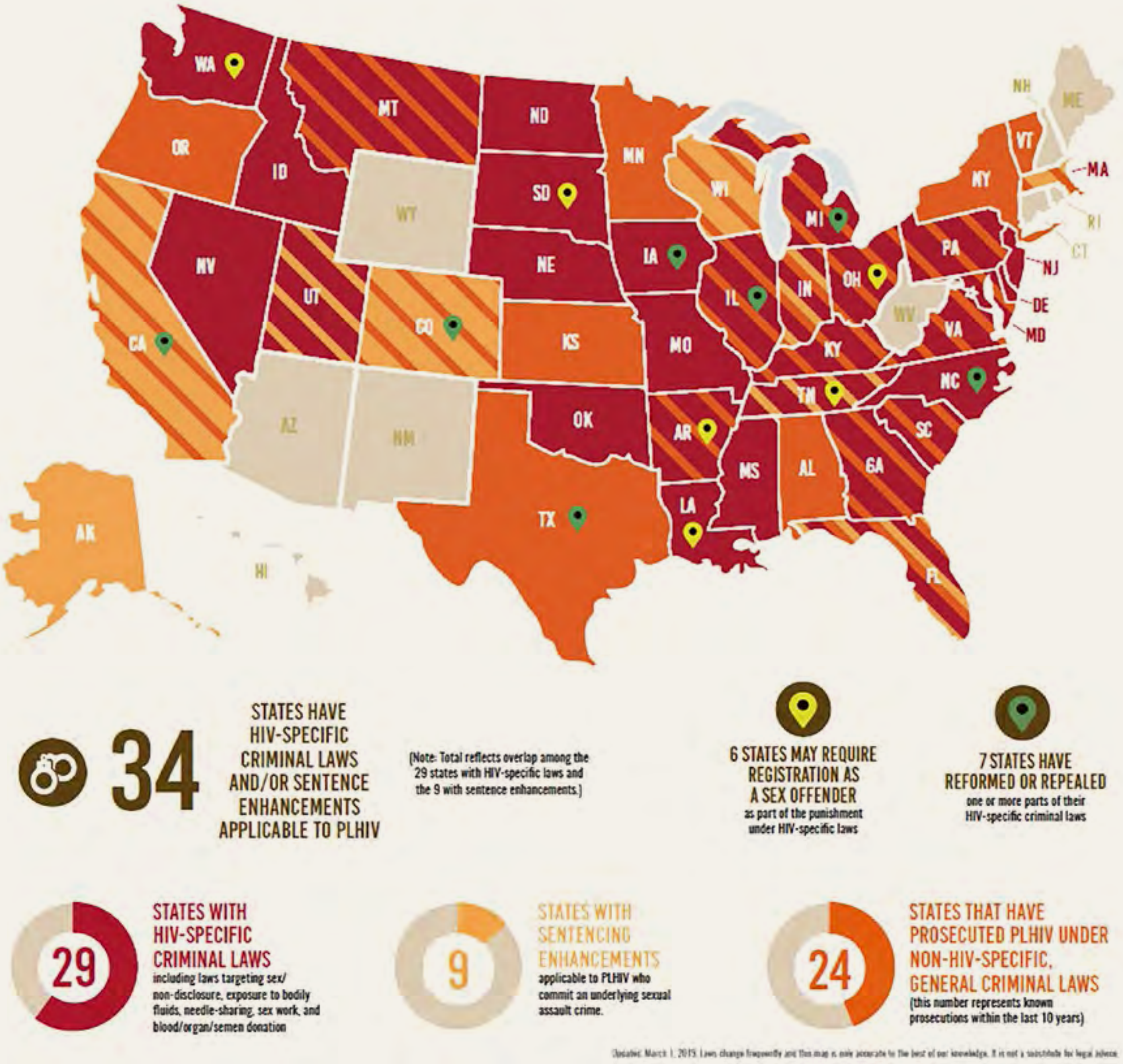
As urban areas tend to be more inclusive and tolerant, city ordinances often offer an effective avenue for enacting anti-discrimination and other human rights provisions. However, many states have acted to "preempt" the right of cities or counties to legislate on particular issues.[48] As of 2017, three states—Arkansas, North Carolina and Tennessee—had explicit statutes to preempt local anti-discrimination ordinances.[48] As preemption grows in popularity in state capitals, local efforts to pass human rights ordinances will need to cultivate champions and build support among state legislators to turn back preemption efforts.

End HIV criminalization

In a misguided effort to prevent new HIV infections, 34 states have enacted laws that criminalize HIV exposure, non-disclosure, or transmission.[49] In addition to stigmatizing people living with HIV and reducing the incentive of people to learn their HIV status, these laws also lack scientific basis, as antiretroviral therapy effectively eliminates the risk of further HIV transmission.[50] Studies have found that Black people living with HIV are most likely to be prosecuted and imprisoned under these HIV criminalization statutes.[51] [52] [53] In one recent Florida case, a jury found that a Black man living

HIV Criminalization in the United States

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



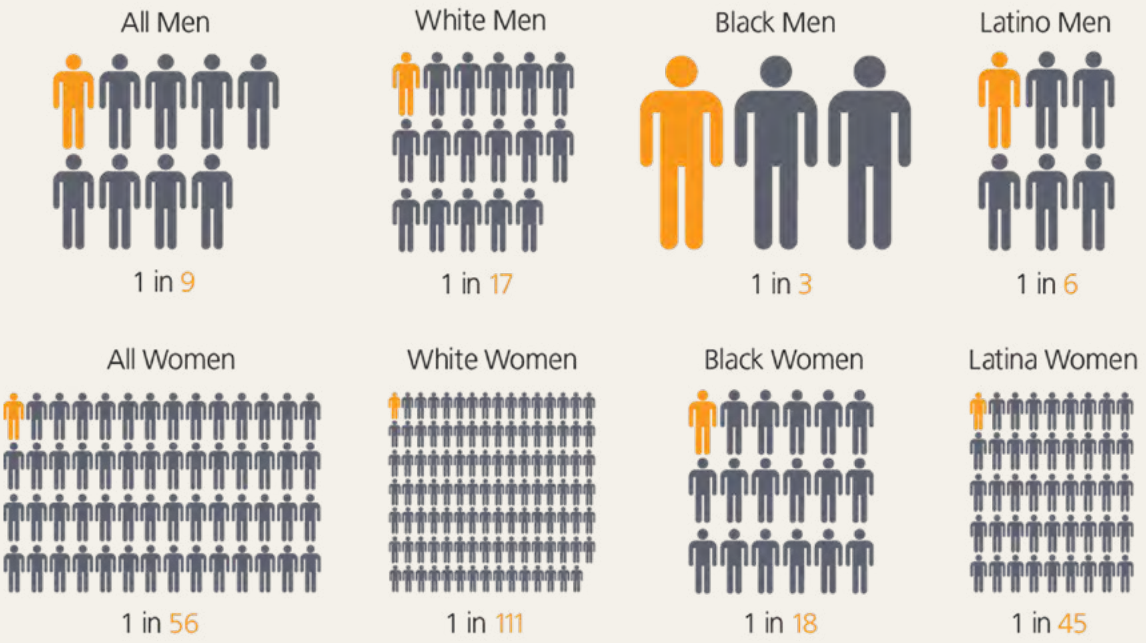
Source: Center for HIV Law and Policy, https://www.hivlawandpolicy.org/sites/default/files/CHLP%20HIV%20Crim%20Map%20 030119.pdf

with HIV was a threat to the public, even though the state's own criminal score sheet found an insufficient threat to warrant jail time.[54] Seven states have reformed or repealed such laws, and their courage and commitment to ground their approach to HIV prevention in non-discrimination principles and sound scientific evidence now need to be followed by those states that retain such counterproductive laws.

Guarantee comprehensive and medically accurate sex education

Equipping young people with the skills they need to avoid HIV acquisition and to live full and healthy lives if they acquire HIV requires investments in comprehensive and medically accurate sex education. To be truly comprehensive and people-centered, sex education needs to be inclusive of gender

Lifetime Likelihood of Imprisonment of U.S. Residents Born in 2001



Source: Bonczar, T. Prevalence of Imprisonment in the U.S. Population, 1974-2001. Washington, DC: Bureau of Justice Statistics. (The Sentencing Project, https://www.sentencingproject.org/criminal-justice-facts/)

identity and the diversity of sexual attraction and expression. A good example is California's 2019 update of its Health Education Curriculum Framework, which recommends the use of "gender-neutral and LGBTQ-inclusive language."[55] Unfortunately, 21 states do not mandate sex education in schools.[56] And 33 states do not require that any sex education provided to young people be medically accurate.[56] In the South, only four states demand medical accuracy for sex education provided to young people.[56]

Ensure unfettered access to comprehensive sexual and reproductive health

Every person possesses the fundamental human right to autonomy in decision-making regarding their sexual and reproductive health. For example, women living with HIV have the right to exercise the full spectrum of their sexual and reproductive rights, including deciding when to be sexual and whether to have children.[57] Realizing this fundamental right demands ready access to medically accurate and person-centered education and counseling, contraception, family planning, and abortion services. However, a growing number of states have taken steps to undermine the federal guarantee of contraception access in the Affordable Care Act and to restrict access to abortion services. In 2018, the Guttmacher Institute reported that 29 states, including every state in the South, were hostile or extremely hostile to abortion rights.[58]

Broadly reform the criminal justice system

The breadth, uniqueness and cruelty of America's prison industrial complex and addiction to mass incarceration are among of the clearest and most painful legacies of slavery.[59]

While Americans make up roughly 5% of the world's population, the U.S. accounts for 21% of all prisoners.[11] The weight of mass incarceration in the U.S. is disproportionately borne by Black communities. Among Black men born in 2001, it is projected that one in three will be imprisoned during their lifetime.[60] Discriminatory practices toward Black Americans stretch across the criminal justice system, with one study finding that unarmed Black people are 3.5 times more likely to be shot by police than unarmed whites.[61]

Studies have linked the mass incarceration of Black Americans with increased risk of HIV acquisition in Black communities.[62] In particular, the disruption of family structures and neighborhood networks as a result of mass incarceration is associated with increased risk of transmission of HIV or other sexually transmitted infections.[63] In addition, people living with HIV risk discontinuity of life-saving care both during their incarceration and once they are released from correctional settings.

At a time when crime rates are at historic lows[64], a bipartisan consensus has emerged on the need to reform America's approach to mass incarceration, but the kind of concrete action needed to dismantle the country's punitive, costly and counterproductive approach to law enforcement has yet to be taken. Urgent, immediate action is needed to end America's system of mass incarceration, to end the impunity of law enforcement agents who abuse Black people (including but not limited to sex workers and people who use drugs), and eliminate cash bail. At the same time, concerted efforts should focus on improving HIV services for the currently and formerly incarcerated, including support for re-entry into the community and continuity of care and services.

Increase Black voter turnout to increase the number of elected officials who advance policies and systems that are critical to the well-being of Black people

Ideally, the vote ought to be the most effective means of ushering in the kind of legal and policy reform needed to remove the structural disadvantages that Black communities confront. Even in the most conservative states in the country, Black people represent a decisive share of the voting public: 38% of the state population of Mississippi, 32% in Louisiana, 31% in Georgia, 27% in South Carolina, and 26% in Alabama.[65] However, in recent years, numerous states have taken steps to withhold or diminish Black people's ability to exercise their constitutional voting rights.[66] Since 2010, at least 25 states have curbed voting rights by implementing voter ID requirements, restricting opportunities to register to vote, closing voting places or reducing early voting.[67] In addition to these voting restrictions, racial gerrymandering practices have also weakened Black voters' political power.[68] As of October 2019, 11 states withheld voting rights for people convicted of a felony[69], although Florida voters in 2018 overwhelmingly approved a ballot proposition the restored the voting rights of 1.5 million people with a felony conviction on their record.[70]

These patently unfair and unconstitutional efforts to diminish the ability of Black voters to effect change have generated an array of initiatives by Black leaders such as Stacey Abrams (fairfight.com) and Eric Holder to fight voter suppression. In an era of vituperative partisan warfare, the ability of Black communities to influence the way they are governed should be a matter of right and wrong rather than partisan advantage. While working to roll back voter restrictions, Black communities need to redouble efforts to register voters and promote robust voter turnout. In this regard, the New Georgia Project focuses on registering and civically engaging Georgia residents, with a particular focus on the "New American Majority" that includes people of color, young people ages 18-29 and unmarried women.[71]

Advance accountability by creating state/local scorecards on policy and enabling environment

Multi-sectoral HIV racial and social justice coalitions at the state and local level should create scorecards to monitor the success of their governments in creating a policy environment that supports an effective HIV response. Not only will these scorecards increase the accountability of state and local decision-makers, but they will also underscore for diverse audiences how HIV is integrally linked with progress on broader racial and social justice issues.

Grassroots Action to Fight HIV Among Black Women

In 2006, Florida health authorities issued a report that radically altered the landscape of the state's HIV response and galvanized unprecedented mobilization efforts in Black communities across the state. The report found that Black women in Florida were nearly 19 times as likely to be diagnosed with HIV as white women.

The shock generated by the report resulted in the formation of Sistas Organizing to Survive (SOS), a grassroots mobilization of Black women to fight for health equity and racial justice in the state's response to HIV. Public health workers at the state and local level joined with grassroots activists to launch a movement that continues to endure.

"We wanted to ensure that efforts to address the HIV crisis in Florida among Black women were incorporated into not only our daily conversations but into programming and policy initiatives," said Evelyn Ullah, a public health professional who at the time was a health officer for Miami-Dade County. "We wanted to make sure that every day was an awareness day when it came to Black women."

The initial focus of SOS was the convening in 2008 of the first-ever statewide conference on Black women and HIV in Orlando, which drew more than 800 attendees. "I don't know of any words to describe what the meeting was like and the impact it had," said Leisha McKinley-Beach, the current head of the Institute's health department work and at the time the leader of HIV prevention efforts at the Florida Department of Health. "Everyone wanted to be a part of it. From activists in Miami-Dade bringing busloads of women to Orlando to Black women working in the health department contracts and finance department requesting approval to attend, there was this sense of pride that the state was finally focusing on the impact of HIV among Black women."

There are two audiences for SOS advocacy. First, SOS aims to influence public health policies and programs, in part by helping decision-makers understand and address the unique factors that increase Black women's vulnerability and the special barriers to service access that they face. A key focus in this regard is HIV testing, as SOS set a target to have Florida test at least 100,000 Black women annually by 2010. "[The Orlando meeting] introduced a whole new concept to me about this time," McKinley-Beach

recalls. "There was a group of Black women motorcycle enthusiasts who took on this effort. Everywhere they went, they promoted testing, and several members were actually approved by the state to provide testing services." SOS reached its testing goal by 2010 and actually sustained this level of testing for several years after the deadline.

Black communities across the state are the second audience for SOS. "We do a lot of non-traditional things to keep women engaged in HIV," said Kalenthia Nunnally, who spearheads the work of the SOS chapter in Miami-Dade. "For example, we recently engaged over 150 Black women in a single weekend, providing access to testing, condoms and PrEP. SOS is a full-time undertaking here in Miami. Everywhere you go, everybody knows about SOS and our work."

Important lessons can be drawn from the SOS experience in Florida. First and foremost, extraordinary things can be achieved by combining the expertise of public health agencies with the ownership, leadership and passion of grassroots activists.

However, another lesson is that sustaining this grassroots energy is essential to preserve and build on early achievements. Unfortunately, there are signs that the momentum in meeting the HIV challenge among Black women in Florida is waning. The founder of SOS Ronald Henderson, a senior ranking staff person at the state health department who was invested in sustaining the initiative, passed way in October 2019. The number of Black women testing annually has fallen from the levels achieved in the aftermath of the SOS statewide conference. The most recent HIV prevention plans in Florida do not prioritize Black women as a distinct group. Today, two Black women in Florida are diagnosed with HIV every day.

In early 2020, one of the few SOS chapters in the state that remains active is in Miami-Dade, home to one in four HIV diagnoses in Florida. The lack of dedicated resources for SOS activities, combined with the fact that several key SOS leaders have moved on to other jobs, has contributed to a lessening of energy toward addressing the HIV-related needs of Black women in Florida.

The need to renew and revitalize grassroots work to fight HIV among Black women in Florida is clear. "We don't get to the end of the epidemic, even with the best blueprint, if Black women don't get prioritized in HIV planning processes," said McKinley-Beach. "Unfortunately, our champions nationally are still few and far between."


ARTIST
TIME TRAVELLER
VALENTINO UNDERCOVER

PILLAR 2

Provide resources and services that address the fullness, richness, potential and expertise of Black people and mitigate social and structural factors that worsen health outcomes in Black communities

In the U.S. HIV response, great attention has rightly focused on the biomedical tools that can prevent HIV infections and HIV-related illness and death. Given the multiple factors that increase HIV vulnerability in Black communities and affect Black people's ability to access and benefit from biomedical services, healthcare for Black people affected by HIV needs to be holistic in its approach, addressing each individual in their fullness. A person's ability to thrive on HIV biomedical tools is inevitably affected by whether they have stable housing, sufficient food, protection from violence and abuse, untreated mental health conditions or a substance use disorder.

Ensure that health and supportive services are comprehensive, integrated and holistic and they effectively address the lived realities of Black people and meet the needs, preferences and expectations of Black communities

Individual providers, clinics and service systems must be prepared—professionally and culturally—to provide the comprehensive, people-centered services that prevent HIV infection or optimize the health and well-being of the person living with HIV.

Broadly integrate trauma-informed care into healthcare service provision

It is estimated that 70% of people living with HIV have experienced trauma, such as the sudden, unexpected loss of a loved one, a physical or sexual assault, or childhood abuse.[72] Nationally, Black people are more likely than whites to have a diagnosis of post-traumatic stress disorder.[73] In one primary care population in Washington D.C., 65% of Black patients were found to have experienced a traumatizing event.[74] According to a 2019 study, the experience of discrimination is significantly associated with post-traumatic stress disorder among Black adults.[75]

All too often, service providers treat traumatized individuals as "problem clients" rather than recognizing how experience of prior trauma can affect an individual's ability to participate as a partner in HIV service delivery. Rather than blame clients, there is growing recognition of the importance of preparing providers and service systems to diagnose and respond holistically to trauma in their clients.[72] "Trauma-informed care" takes an intersectional approach that recognizes the overlap of social identities—such as gender identity, sexual orientation, race/ethnicity—and co-morbidities (such as poverty, homelessness, addiction and mental health) that can affect an individual's vulnerability to trauma.[72]

The New Jersey Department of Health is undertaking a statewide training and capacity-building program to ensure that all of its funded HIV service providers are able to integrate trauma-informed care into their structure, culture and services.[76] Lessons learned from New Jersey's experience need to be taken on board nationally in order to make the HIV service infrastructure as welcoming and responsive as possible to the realities of the lives of people living with HIV.

Integrate self-care and mental health in all HIV and health services delivery

People living with or at risk of HIV are more likely than the U.S. population as a whole to have mental health problems, and these mental health issues can have a substantial impact on a person's ability to protect themselves from HIV infection or remain engaged in HIV care.[77] Accordingly, mental health services need to be integrated across all HIV services.[77] Achieving full integration of services will demand action not only at the service provider level but also among federal and state governments, as siloed systems for funding HIV and mental health services are an important reason why these services are so seldom integrated.

Integrate harm reduction into all HIV services and promote evidence-based harm reduction throughout the Black community

Substance use can increase the risk of HIV acquisition (both through the sharing of injection equipment and by increasing sexual risk taking) and also diminish the ability of people living with HIV to access and remain engaged in HIV care. In 2017, Black people represented 48% of all people living with HIV who acquired HIV via injecting drug use.[42] Although primarily regarded as a problem of white communities, opioid use is growing most rapidly in Black communities, with Black Americans experiencing a substantial increase in opioid death rates compared to whites in recent years.[78] Likewise, use of crystal methamphetamine, which is rapidly increasing in many parts of the U.S., is on the rise on Black communities as well.[79]

Harm reduction strategies—a package of services that includes needle and syringe exchange, opioid substitution therapy and access to behavioral and biomedical healthcare—reduce the risks associated with drug use and are strongly recommended by public health authorities as a pillar of HIV services.[80] [81] [82] However, effective integration of harm reduction strategies in HIV services is hindered by a host of factors, including funding prohibitions by federal and many state governments, community resistance to such programs, and the use of distinct and siloed funding mechanisms for HIV and substance use treatment services. An urgent effort is needed to overcome these barriers to address holistically the healthcare and social services needs of people who use drugs and who are also affected by HIV.

Develop engagement strategies and service platforms for key Black subpopulations

Holistic service platforms are especially scarce for certain parts of Black America. For example, Black cis men are often a forgotten segment of the Black community when it comes to HIV, notwithstanding the fact that more than 49,000 Black men in 2017 were living with heterosexually acquired HIV.[41] Nationally, nearly one in three trans people lack access to healthcare, often due to the absence or shortage of providers who have the capacity to address their needs.[83] And many same-gender-loving men, especially those living outside urban areas, often have few, if any, options to obtain comprehensive, non-judgmental care and services.[17] Focused action is needed to ensure that these and other disproportionately affected communities in Black America have service options that are tailored to meet their needs.

Integrate peer recovery coaching, peer mentors, community clubhouses and other people-centered approaches for people living with HIV

Although service providers play an essential role in managing HIV infection, self-care is equally important for a chronic condition such as HIV. Peer-based, community-centered approaches have been shown to improve HIV outcomes. Community-based strategies that empower, support and mobilize people living with HIV should be prioritized in the allocation of new resources for ending the HIV epidemic.

Invest in services and policies that mitigate the social factors that increase HIV vulnerability in Black communities, impede health service utilization and worsen health and social service outcomes

Social and structural approaches that reduce vulnerability and empower Black communities are vital to sustainable progress toward ending HIV. Few of these social and structural interventions are likely to succeed without the dismantling of America's system of mass incarceration, which significantly affects Black families, friends, loved ones and communities across the country.

Massively increase investments in affordable housing, implement policy reforms to expand housing access, and ensure linkage to housing assistance in all HIV services

America is in the midst of a housing crisis, with gentrification and counterproductive restrictions on the creation of affordable housing fueling alarming national increases in homelessness.[84] Achieving and sustaining viral suppression is difficult, and in most cases impossible, when the person living with HIV is homeless or unstably housed. Likewise, homelessness is also associated with increases in behaviors that can lead to HIV transmission.[85] A major effort—led by the federal government and prioritized in states and cities where homelessness is most prevalent and affordable housing most scarce—is an urgent national priority.

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The shock generated by the report resulted in the formation of Sistas Organizing to Survive (SOS), a grassroots mobilization of Black women to fight for health equity and racial justice in the state's response to HIV. Public health workers at the state and local level joined with grassroots activists to launch a movement that continues to endure.

"We wanted to ensure that efforts to address the HIV crisis in Florida among Black women were incorporated into not only our daily conversations but into programming and policy initiatives," said Evelyn Ullah, a public health professional who at the time was a health officer for Miami-Dade County. "We wanted to make sure that every day was an awareness day when it came to Black women."

The initial focus of SOS was the convening in 2008 of the first-ever statewide conference on Black women and HIV in Orlando, which drew more than 800 attendees. "I don't know of any words to describe what the meeting was like and the impact it had," said Leisha McKinley-Beach, the current head of the Institute's health department work and at the time the leader of HIV prevention efforts at the Florida Department of Health. "Everyone wanted to be a part of it. From activists in Miami-Dade bringing busloads of women to Orlando to Black women working in the health department contracts and finance department requesting approval to attend, there was this sense of pride that the state was finally focusing on the impact of HIV among Black women."

There are two audiences for SOS advocacy. First, SOS aims to influence public health policies and programs, in part by helping decision-makers understand and address the unique factors that increase Black women's vulnerability and the special barriers to service access that they face. A key focus in this regard is HIV testing, as SOS set a target to have Florida test at least 100,000 Black women annually by 2010. "[The Orlando meeting] introduced a whole new concept to me about this time," McKinley-Beach

recalls. “There was a group of Black women motorcycle enthusiasts who took on this effort. Everywhere they went, they promoted testing, and several members were actually approved by the state to provide testing services.” SOS reached its testing goal by 2010 and actually sustained this level of testing for several years after the deadline.

Black communities across the state are the second audience for SOS. “We do a lot of non-traditional things to keep women engaged in HIV,” said Kalenthia Nunnally, who spearheads the work of the SOS chapter in Miami-Dade. “For example, we recently engaged over 150 Black women in a single weekend, providing access to testing, condoms and PrEP. SOS is a full-time undertaking here in Miami. Everywhere you go, everybody knows about SOS and our work.”

Important lessons can be drawn from the SOS experience in Florida. First and foremost, extraordinary things can be achieved by combining the expertise of public health agencies with the ownership, leadership and passion of grassroots activists.

However, another lesson is that sustaining this grassroots energy is essential to preserve and build on early achievements. Unfortunately, there are signs that the momentum in meeting the HIV challenge among Black women in Florida is waning. The founder of SOS Ronald Henderson, a senior ranking staff person at the state health department who was invested in sustaining the initiative, passed way in October 2019. The number of Black women testing annually has fallen from the levels achieved in the aftermath of the SOS statewide conference. The most recent HIV prevention plans in Florida do not prioritize Black women as a distinct group. Today, two Black women in Florida are diagnosed with HIV every day.

In early 2020, one of the few SOS chapters in the state that remains active is in Miami-Dade, home to one in four HIV diagnoses in Florida. The lack of dedicated resources for SOS activities, combined with the fact that several key SOS leaders have moved on to other jobs, has contributed to a lessening of energy toward addressing the HIV-related needs of Black women in Florida.

The need to renew and revitalize grassroots work to fight HIV among Black women in Florida is clear. “We don’t get to the end of the epidemic, even with the best blueprint, if Black women don’t get prioritized in HIV planning processes,” said McKinley-Beach. “Unfortunately, our champions nationally are still few and far between.”

Faith-Based Action to Combat Stigma and Promote HIV Prevention

The roots of the BTAN Melbourne chapter in Florida can be traced back to 2011, when a community coalition was formed in the state's central coastal region to reduce HIV-related stigma. The Stop the Stigma Coalition supported the work of more than 40 local Black churches to increase their congregants' awareness of HIV, according to John Curry, who leveraged lessons he learned through participation in the Institute's HIV Science and Treatment College to help galvanize this local coalition.

"I am a person living with HIV," Curry said. "We implemented the Stop the Stigma coalition because there are individuals who are still in chains, still in bondage, around their HIV status. But [people living with HIV]I deserve the same respect as individuals who are not HIV-positive."

"When we began Stop the Stigma, we had so many members of our congregation we had lost to the virus," said Gail Robinson. "There was so much misinformation about HIV. It was very important that we start giving correct information, but that had to come from people who looked like members of our community in order for them to hear it and understand it."

Eventually, the Stop the Stigma Coalition evolved into the BTAN Melbourne chapter. "We are truly grassroots," said Curry. "We have 20 or more people who are active in the chapter, but none of them work full-time in HIV. BTAN Melbourne has become a passion for most of our members. They go to their regular jobs during the day, but on the weekend or during the week when we have an event, they are truly committed."

The foundation of BTAN Melbourne is the MaxOut Church, which is affiliated with the non-profit MaxJax community development organization. MaxJax serves as the fiscal agent for BTAN Melbourne, while the church serves as the home of local BTAN meetings.

"Faith leaders play a huge role in helping get to the end of HIV stigma," Curry said. "Congregations follow their pastor, so the pastor plays an intricate role in ending the epidemic."

"As a pastor, it is clear to me that churches must be involved in responding to HIV," said Leo Stoney, pastor of the MaxOut Church.

"Your congregants see you on a week to week basis. In order for this thing to end we must be involved." According to Thompson, the willingness of local pastors to participate in HIV testing events has encouraged countless churchgoers to be tested, increasing the reach and impact of BTAN Melbourne's work.

In addition to the strength it derives from the commitment of the MaxOut Church, BTAN Melbourne also benefits from its affiliation with the MaxJax community development efforts, which enables the local BTAN chapter to position its work within the broader context of people's lives. "AIDS is just one epidemic," Pastor Stoney said. "We have an epidemic of homelessness, an epidemic of drugs. . . We are living in the heart of the foundation of epidemics. Through MaxJax, we have reached countless individuals and changed their lives. We are able to feed the homeless, build low-income housing, open a health clinic."

BTAN Melbourne has served as the catalyst to engage the broader Black community in the HIV fight. "We have the support of AIDS service organizations, the support of the city council, the support of sororities and fraternities, other churches, law enforcement, schools," said Curry.

BTAN Melbourne exemplifies the kind of selfless commitment of Black communities that has the potential to end HIV. "You have to recognize the journey and the level of sacrifice it takes to do something at the grassroots level," Pastor Stoney said. "You cannot be as productive as you should if there is a loophole in commitment."

But relying on grassroots volunteers inevitably encounters a limit, especially if funders fail to provide sufficient resources to support grassroots work. "A lot of the time work in rural areas is overlooked when HIV funding is disseminated," Curry said. To obtain the financing it needs to build on its work, BTAN Melbourne is seeking funding from philanthropists, pharmaceutical companies, health departments and federal agencies to support its innovative grassroots stigma initiative.

PILLAR 3

Ensure universal access to and robust utilization of high-quality, comprehensive, affordable and culturally and gender-affirming healthcare to enable Black people to live healthy lives in our full dignity

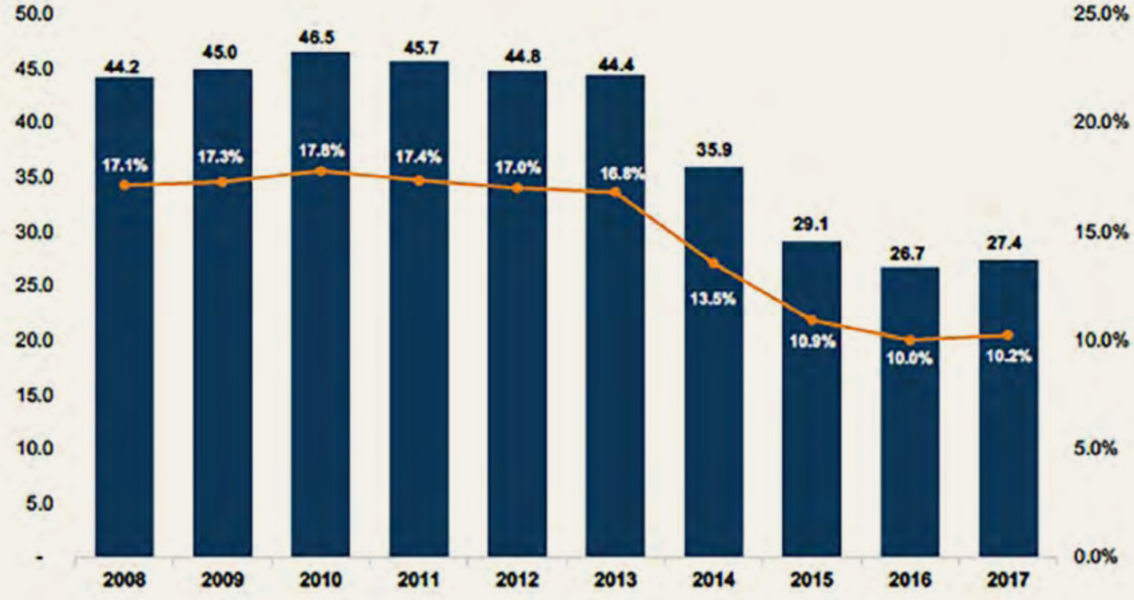
Although available biomedical tools have the potential to end the epidemic, we can realize the full potential of these tools only if those who need them are able to use them. Putting these powerful medical tools to use involves two essential steps. First, people who could benefit from these tools must have meaningful, unfettered access to affordable healthcare services. Second, having access, people who need these biomedical tools require the knowledge, motivation and people-centered care to use healthcare services.

Ensure that everyone has access to people-centered, affordable healthcare services

Access to good-quality, affordable healthcare is a basic human right—one that the U.S. consistently denies to millions of its people. The U.S. is alone among wealthy, industrialized countries in failing to ensure universal health coverage.[104] Even with the Affordable Care Act (ACA) in place, 27.5 million Americans lack health coverage.[105] For the first time in 10 years, the number of uninsured increased in 2018, as a result of the Trump Administration's hostility to the ACA, as manifested by efforts to overturn the law and by the withdrawal of funding to support enrollment efforts.[106] America cannot end the HIV epidemic while simultaneously working to dismantle the program that has brought health coverage to 20 million Americans who previously lacked it.[107]

The ACA has generated enormous health benefits for Black Americans. Although Black people in 2018 were more than one-third more likely than white Americans to lack health coverage, this represents a remarkable improvement over the year prior to ACA implementation, when the uninsured rate in the Black population was more than twice the rate among whites.[108] Following the first year of implementation of the ACA, the uninsured rate among Black people living with HIV fell by one-third.[109]

Number of Uninsured and Uninsured Rate Among the Nonelderly Population, 2008-2017



NOTE: Includes nonelderly individuals ages 0 to 64.
SOURCE: Kaiser Family Foundation analysis of 2008-2017 American Community Survey (ACS), 1-Year Estimates.

Enact further healthcare reform to achieve universal health coverage

The U.S. now needs to build on the ACA to achieve the universality of health coverage that has been realized in every other major industrialized country. Multiple paths are available to attain universal health coverage, as coverage schemes in other wealthy countries include both single-payer systems and multiple-payer systems.[104]

In the immediate term, expand Medicaid in all states

Until such time as the U.S. achieves universal health coverage, all states that have failed to expand Medicaid, as allowed under the ACA, should take immediate steps to do so. As of early 2020, 14 states, including a majority of Southern states, had not expanded Medicaid, even though the federal government covers 90% of all costs associated with expansion.[110] An expanded Medicaid program markedly increases access to HIV services, as the percentage of people living with HIV who lack health insurance is nearly four times higher in non-expansion states than in states that have expanded Medicaid.[111] The number of states that have opted against expanding Medicaid has declined by one-third since 2015, when 21 states had yet to expand the program.[112] In 2019, Virginia, a Southern state, expanded its Medicaid program, demonstrating the fluidity of the politics of Medicaid expansion in the country's most conservative region.

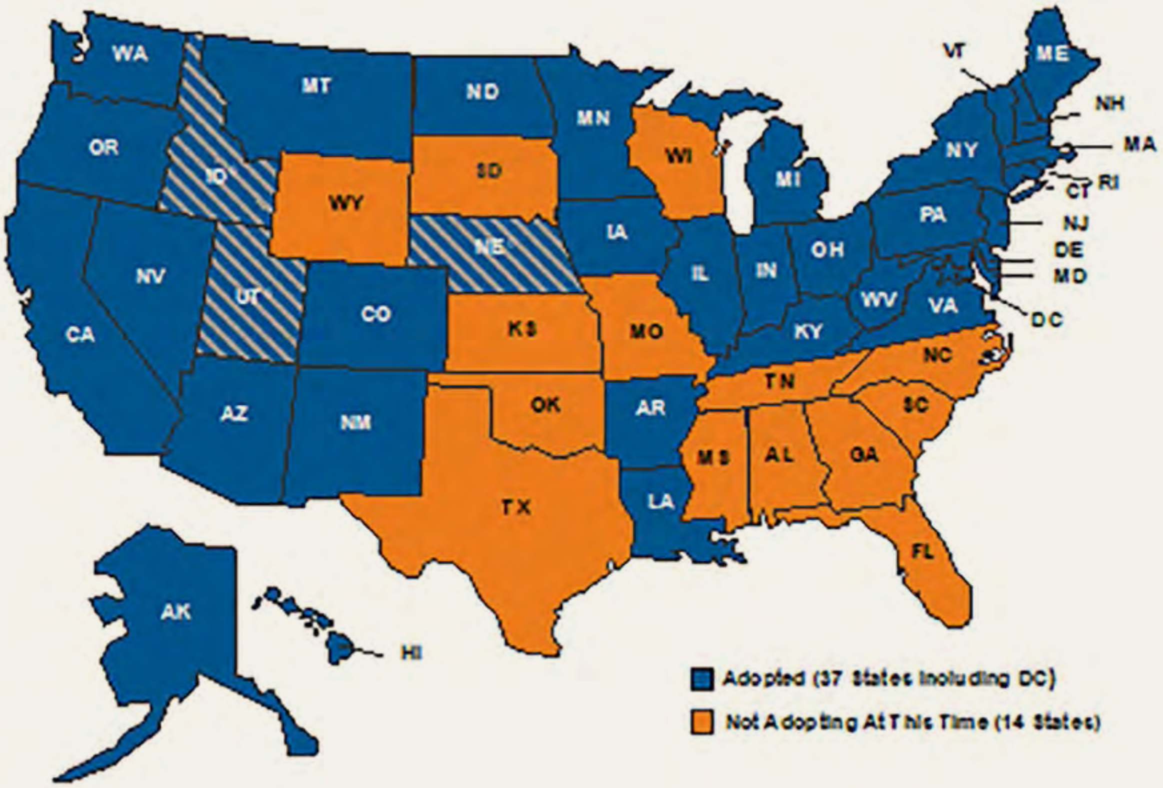
Drive down prices of drugs and other pharmaceutical products

In addition to expanding health coverage, other policy steps are required to enhance the accessibility and affordability of healthcare services. Policy reform is needed to bring down the prices of drugs and other health products. On average, Americans pay nearly twice as much for pharmaceutical products as healthcare consumers in other wealthy countries.[113] Studies have found that costs associated with PrEP use have a direct, inverse correlation with uptake of PrEP—the more costly it is to use PrEP, the fewer people who will use it.[114] A recent analysis by leading health economists found that the country could double the number of transmissions prevented through PrEP by bringing the price of PrEP down.[114]

Undertake focused implementation science research led by Black researchers to identify and address barriers to healthcare utilization

Action is also needed to understand and address the factors that affect people's use of healthcare services. In many Black communities, routine use of health services, especially for preventive care, is uncommon, underscoring the importance of developing new community norms for care-seeking. Major new investments are needed in implementation science led by Black researchers to identify strategies to improve HIV service access, utilization and outcomes in Black communities. Black researchers have an unmatched motivation to participate in efforts to increase the knowledge base for effective action to address the health needs of Black communities, they bring their own personal insights to bear in understanding and studying the factors that affect health outcomes among Black

Status of State Medicaid Expansion Decisions



NOTES: Current status for each state is based on KFF tracking and analysis of state activity. [1]Expansion is adopted but not yet implemented in ID, NE, and UT. (See link below for additional state-specific notes).

SOURCE: "Status of State Action on the Medicaid Expansion Decision," KFF State Health Facts, updated November 15, 2019.
https://www.kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/

Source: Henry J. Kaiser Family Foundation people, and they often are much better able to build strong working relationships with Black community organizations and institutions. Specific efforts by Black researchers are needed to examine and better understand community perceptions about HIV technologies and HIV-related health services.

Ensure that the healthcare system has the capacity and incentives to provide high-quality, people-centered, non-discriminatory healthcare services to all Black people

When Black people encounter the healthcare system, they seldom see providers who look like them. While Black people represent 13% of the U.S. population, only about 6% of physicians and surgeons nationwide are Black.[115] When they access a system in which comparatively few Black healthcare professionals work, Black patients often experience discrimination—not only from healthcare providers but even in the algorithms used to refer patients for specialty care.[116] [117] These negative experiences reinforce the medical mistrust that is common in Black communities [118] [119] [120], deriving from the long history of racism in medical and public health practice, including but not limited to the infamous Tuskegee Syphilis Study. Where medical mistrust exists, delays in seeking needed care frequently result, leading to further deterioration of health, poorer prognosis and missed opportunities for preventive interventions. And when healthcare delivery itself is affected by racist attitudes or structures, the care that Black patients receive is often of poor quality.[121]

Mandate training and certification in anti-racism and cultural competence/humility

All HIV service and healthcare providers should have the capacity to provide culturally competent, appropriate and humble services to individuals of all races, ethnicities and country of origin. An approach worth emulating is California's new legislation mandating implicit bias training for healthcare and court personnel.[122] Likewise, health departments and medical clinics should avail themselves of anti-racism trainings, such as those provided by the People's Institute for Survival and Beyond to health departments in Chicago and North Carolina.[123]

Increase the number of Black healthcare providers

Academic institutions should be incentivized to increase the number of Black recipients of medical degrees (e.g., MDs, RNs, NPs). Steps should also be taken—such as through loan relief, personalized outreach, etc.—to support Black students to seek education, training and certification as healthcare professionals.

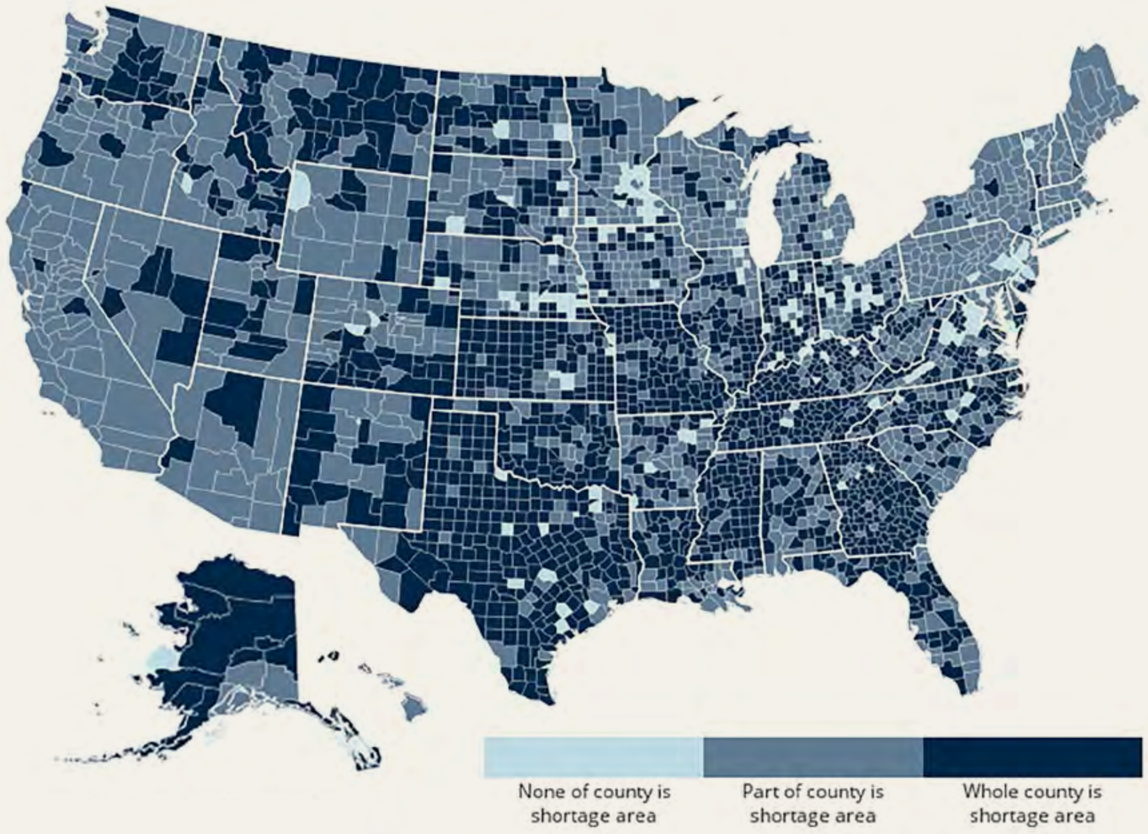
Eliminate deterrents to health service utilization

Factors that discourage Black people from using health services should be eliminated or minimized.

Standardize best practices for clinic operations to make them optimally user-friendly for Black clients

Clinical settings frequently function poorly, discouraging individuals from seeking the services they need. For example, patients who are Black on average experience waiting times for health services that are 25% longer than for white patients.[124] Focused capacity-building

Health Professional Shortage Areas: Primary Care, by County, 2019



Source: data, HRSA, gov, October 2019. (Rural Health Information Hub, https://www.ruralhealthinfo.org/charts/5)

assistance should be provided to help clinics become more client-friendly and efficient. In this regard, healthcare providers should be encouraged and/or required to use every opportunity to provide client-focused support, such as inquiring about adherence and associated barriers every time a prescription is filled.

Use innovative technologies and practices to expand and enhanced access to quality healthcare services in rural and medically underserved areas

Hundreds of rural counties across the U.S. are experiencing an acute shortage of primary care services.[125] Healthcare shortages are especially pronounced in the South, where Black America's HIV epidemic is most heavily concentrated, and has been exacerbated by an increasing number of rural hospital closures, which in turn have been correlated with increased mortality in rural communities.[126] Strategies to address primary care shortages in rural areas include increased use of telemedicine and creation of smaller health centers to deliver health services in areas affected by hospital closures.

Eliminate healthcare siloes and provide holistic, coordinated care

Government-funded grant programs for particular health priorities—such as HIV and sexual and reproductive health—have undoubtedly expanded access to services in these public health areas. However, the singular focus of such programs can impede efforts to provide holistic, comprehensive, patient-focused health services. HIV programs seldom address such issues as contraception, while many family planning services often lack expertise to address their patients' HIV-related needs. New approaches are needed that preserve a focus on these critical public health priorities while at the same time incentivizing providers to provide holistic care and support.

Undertake focused, people-centered efforts to address healthcare utilization deterrents faced by people affected by the criminal justice system

Reform of mainstream health services will not, on its own, address the myriad needs of people affected by America's carceral system. Many incarcerated people living with HIV struggle to obtain optimal care and frequently experience the effects of stigma and breaches of confidentiality, while HIV prevention measures are seldom implemented in many jails and prisons. People living with HIV are routinely released from correctional settings without a comprehensive discharge plan or measures in place to ensure continuity of care or access to high-quality, appropriate health and social services. Especially at a time when the country is beginning to rethink its decades-long expansion of incarceration, a comprehensive effort is needed to improve healthcare utilization and outcomes among people involved in the criminal justice system.

Invest in community-centered and–led initiatives to increase demand for and utilization of healthcare services by Black people

At the same time that access barriers are dismantled, intensified action is needed to encourage greater utilization of healthcare services in Black communities.

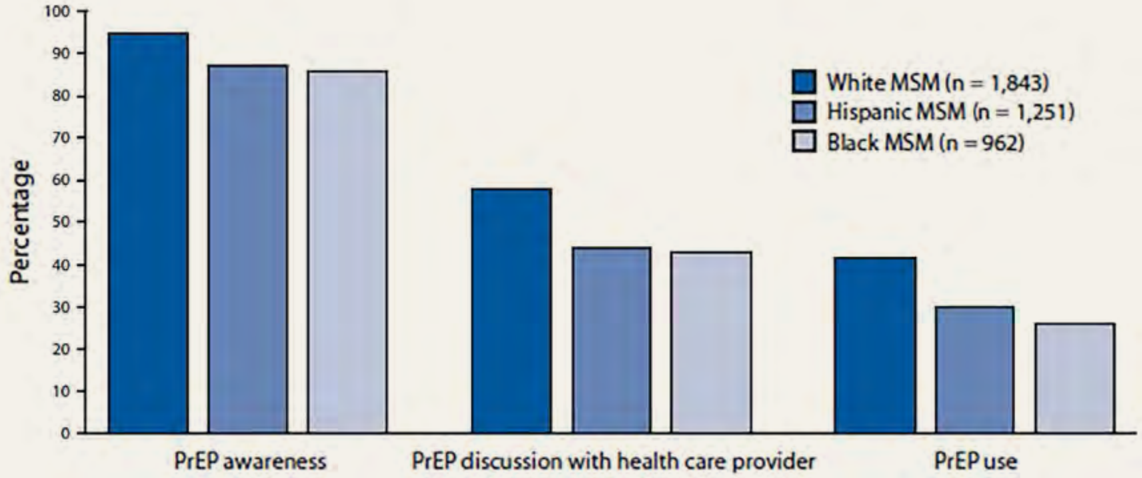
Invest in community-centered, multi-faceted HIV and health literacy initiatives, with particular emphasis on increasing awareness of HIV vulnerability and the benefits of routine HIV testing and use of HIV biomedical options

Compared to whites, Black communities, on average, have lower knowledge of biomedical scientific issues.[127] Lacking strong health-related scientific literacy, Black people may be less likely to recognize their risk for HIV acquisition, learn their HIV status, access antiretroviral therapy if needed, adhere to prescribed regimens and remain engaged in care.[128] Concerted efforts are needed to increase HIV science and treatment literacy in Black communities, including but not limited to real-world and digital ad campaigns, community-based programs, social media, integration of HIV messages and story lines in entertainment and other media platforms. Peer-based interpersonal support is warranted to build the capacity of Black healthcare consumers to share in decision-making regarding their own health and to develop a healthy working relationship with their healthcare provider.

Invest in initiatives that mobilize trained community health workers and patient navigators to support utilization of HIV services and retention in services

A substantial body of evidence demonstrates that trained community health workers often have the ability to reach consumers who are outside mainstream health services and improve healthcare service utilization and outcomes. Drawn from the very communities they serve, community health workers have the ability to help overcome the effects of the longstanding mistrust of the medical establishment in many Black communities.[129] A recent CDC-supported project aided four Southern cities in incorporating community health workers into HIV services, resulting in substantial

Preexposure prophylaxis (PrEP) Awareness, Discussion, and Use, by Race/Ethnicity, Among Men Who Have Sex with Men (MSM) with a Likely Indication for PrEP Use, in 23 Urban Areas, 2017
(N=4,056)



Source: CDC

improvements in retention in care and HIV viral suppression.

Invest in community-based initiatives to increase PrEP uptake among Black people, with specific efforts for key groups within Black communities who need PrEP

Closing the seven-fold difference in PrEP coverage between Black and white people at risk of HIV infection (see p.14) will require multiple, intensive, sustained approaches. Community education programs are needed to increase awareness of PrEP and to address persistent misconceptions about the intervention. Healthcare providers must be educated and encouraged to discuss PrEP with their patients; in 2017, while 58% of white MSM in 23 urban areas reported having discussed PrEP with their provider, the issue was raised by providers only 43% of the time among Black MSM.[130] Black women are also especially unlikely to obtain PrEP when they need it, a pattern that prompted the Black AIDS Institute to develop a PrEP toolkit specifically designed to spur increased uptake among Black women.[131] To help overcome the stigma associated with PrEP in some quarters, PrEP delivery channels should be developed that are outside gay or HIV-branded sites. While a growing number of people are obtaining free PrEP through Medicaid or patient assistance programs, patient costs can often remain substantial for laboratory monitoring, underscoring the need for more expansive and comprehensive reimbursement mechanisms. Innovative use should be made of social networks to increase awareness of PrEP delivery options and overcome the resistance to PrEP among some people. Like any other prevention modality, PrEP will not be appropriate for everyone, but concerted steps are needed to ensure ready access to PrEP for those who desire and could benefit from it.

Prepare communities for new modalities and further innovation in treatment and PrEP

Based on clinical trial results to date, it is likely that long-acting, injectable antiretroviral

therapy and PrEP will be available for use in the foreseeable future[132], and work continues in earnest to develop a preventive vaccine and ultimately a cure for HIV. The advent of long-acting antiretrovirals could expand treatment and prevention options, enable the tailoring of delivery modalities to the needs and preferences of individuals, and potentially improve adherence rates. However, after nearly a quarter of a century of daily dosing of Highly Active Antiretroviral Therapy, it will also represent a monumental shift for many people living with HIV and for healthcare providers and systems. Work is needed now to prepare communities and healthcare systems for the coming paradigm shift[132]—to facilitate rapid uptake and good-quality service delivery for those who desire long-acting antiretrovirals, to educate communities about this new approach, and to address potential concerns or misconceptions. In an effort to engage Black communities in prevention research and help lay the groundwork for future prevention breakthroughs, the Black AIDS Institute has formalized a collaboration with the HIV Vaccine Trials Network (HVTN) order to develop educational materials and hold trainings on HIV vaccine and biomedical prevention research advocacy across the South outh and in cities where HVTN clinical trials are being conducted..

Improve the accountability of the healthcare system (including individual clinics, providers, etc.) to deliver excellent health outcomes for Black communities

The federal government should require, as a condition for receiving EHE funding, that each EHE jurisdiction conduct a race/ethnicity analysis that tracks and annually reports key HIV-related health outcomes (e.g., new HIV diagnoses, AIDS-related deaths, receipt of antiretroviral therapy, retention in care, HIV viral suppression and PrEP uptake). Among jurisdictions demonstrating racial/ethnic disparities in HIV outcomes, eligibility for further EHE funding should be conditioned on the jurisdiction's development and implementation of a corrective action plan to address these disparities. The federal government should provide focused capacity-building support as well as financial incentives to encourage providers to collect and use racial/ethnic data on key HIV outcomes to improve their performance and to enhance the equity of their services. As high and increasing rates of HIV infections clearly reflect public health failures, all stakeholders (from federal agencies to affected communities) should hold county and state governments accountable for high HIV rates, with particular attention to jurisdictions in the South.

Uniting Diverse Partners to Drive Change at the State and Local Level

The Black Treatment Advocates Network (BTAN) aims to serve as a well-informed and well-equipped collective of people who can address barriers specific to Black communities through knowledge transfer, advocacy, mobilization, and community building. BTAN serves as the Black AIDS Institute's boots on the ground—working to implement the changes needed in their own communities in order to end the HIV epidemic. BTAN strives not just to apply a Band-Aid on the problems that affect local communities' ability to fight HIV, but to tackle the root causes of health disparities through building collective power to implement the strategies that can help lead to an HIV-free generation.

Over time, BTAN has emerged as BAI's primary vehicle for catalyzing needed policy and programmatic change in high-burden states and localities. There are now 14 BTAN chapters and 12 BTAN affiliates in place across of the country—most of which are in jurisdictions prioritized for ending the HIV epidemic.

Each BTAN chapter reflects a collaboration between grassroots activists, educators, the HIV workforce, people living with HIV, state and local health departments, and service organizations. Each year, BTAN chapters receive a three-day training that ensures that BTAN members are up-to-date on the latest scientific and policy developments. BTAN chapters meet monthly to share information and plan local activities that aim to improve healthcare outcomes in Black communities. Each BTAN chapter selects a group of core group leaders, who convene monthly with organizers at BAI to review progress and address challenges that have arisen.

With support from BAI, BTAN chapters conduct local events designed to strengthen the local response to HIV. These events can include testing events, town hall meetings focused on specific issues (e.g., PrEP), and other awareness-raising activities. BAI's national campaigns and initiatives are carefully coordinated with BTAN to facilitate effective

dissemination to and engagement of Black communities.

Recently, the Black AIDS Institute also added BTAN affiliates which allows advocates to engage in efforts that are most pressing to their local needs while connecting them to BAI's national efforts. The affiliate model allows activists to implement events as part of the national network while continuing to build toward becoming full-fledged BTAN chapters. As Bryan Jones, a BTAN leader in Ohio, has noted, Black advocates living with HIV can often feel as if they were the only ones speaking up at meetings, and they are frequently in the difficult position of making decisions for their community without having the community in the room. The addition of affiliates, combined with stronger chapters, has helped expand the national BTAN network and keep it abreast of key happenings in local communities. BTAN is structured to make sure the local and national are mutually informing one another.

As the Black AIDS Institute orients its work around the *We the People* blueprint for ending HIV, the role of BTAN chapters and affiliates will become even more prominent in the organization's work. The Black AIDS Institute will actively support BTAN chapters in becoming change agents in state and local planning and implementation toward ending the epidemic. The Black AIDS Institute will build the capacity of BTAN chapters to forge strong working partnerships with multi-sectoral coalitions dedicated to racial and social justice, advocate for Medicaid expansion in states that have yet to expand the program, help persuade decision-makers at the state and local level to undertake essential policy reform, and urge their state and local governments to direct critical resources to Black-led organizations.

PILLAR 4

Build the capacity and motivation of Black communities to be the change agents for ending HIV

Since its creation, the Black AIDS Institute's motto has been: *Our People, Our Problem, Our Solution.* The Institute's working ethos recognizes the central role that communities play in addressing complicated health challenges. If we hope to end HIV, an epidemic that is heavily concentrated in Black communities, Black Americans of all walks of life will need to lead our efforts. This will demand substantially greater ownership of the AIDS fight in Black America as well as major new resources to support community-centered efforts to combat HIV.

Generate broad, enthusiastic ownership in Black communities of the fight to end HIV

Among the achievements of which the Institute is most proud is its work encouraging leading Black organizations and institutions to develop and implement strategic HIV plans. But these signs of community leadership, while laudable, have never been commensurate with the breadth and severity of the HIV crisis in Black America. In recent years, Black Americans are even less likely than before to read about HIV in their newspapers and magazines, to come across HIV on the Internet, to hear about HIV from the pulpit, or to encounter Black celebrities and opinion leaders prioritizing the fight against HIV.

To end HIV in Black America, we must re-energize our HIV champions and cultivate new partners in the Black community. Every part of Black America must be part of the fight to end HIV—elected leaders, faith-based organizations, historically Black colleges and universities, civic and fraternal organizations, Black media, Black artists and celebrities, and ordinary people concerned about their families and communities. To renew and broaden the HIV coalition, HIV in Black America needs to be re-branded as the racial and social justice it is. In the era of social media, we have new opportunities to engage Black Americans in conversations and mobilization in new and exciting ways. There is a resurgence of activism that is happening in Black communities across the country, and HIV surely should be in the center of any activism that is focused on the well-being of Black people.

At the same time that we work to refocus the attention of Black America on the HIV fight, steps should be taken to normalize HIV as a health condition like any other, in order to diminish the stigma associated with HIV and encourage Black Americans to get tested for HIV and access needed prevention and treatment services. Within Black America, we need

to undertake an inter-generational dialogue that works toward a genuine culture change in Black communities that openly addresses the fullness and wholeness of the diversity of Black America. Across all our efforts to re-engage Black communities in the effort to end HIV, we must elevate and promote the voices of Black people living with HIV, including specific steps to elevate young leaders, LGBTQ people in all their diversity, the formerly incarcerated and sex workers.

Allocate sufficient financial resources to enable Black communities to lead efforts to end HIV

The infusion of new funding for EHE planning and implementation, while welcome, should be understood only as an early down-payment on the resources that will be needed to end HIV—especially as this EHE funding borrows heavily from the Minority AIDS Initiative. Substantial new funding will be required, particularly in EHE jurisdictions with comparatively limited tax base.

By 2025, at least 60% of EHE funding should be earmarked for Black-led organizations (i.e., organizations in which Black people account for the senior-most leader (e.g., CEO, executive director), a majority of overall senior leadership, and a majority of the board of directors). In Years 1 through 4, the federal government should ramp up toward this 60% figure by funding larger Black-serving but not Black-led organizations to undertake specified infrastructure-building activities (e.g. sustainable infrastructure for grant-writing and donor engagement, human resources, finance, administration, etc.) with Black-led organizations. This "bridge funding" should decline over time from Year 1 to Year 4, and these infrastructure-building

Lessons from NYC's Progress Toward Ending its HIV Epidemic

In 1990, New York State accounted for roughly one in five people living with AIDS in the U.S., with New York City accounting for the vast majority of these cases.[134] Today, however, as we approach the 40th anniversary of the discovery of the epidemic, New York is on pace to end its HIV epidemic.

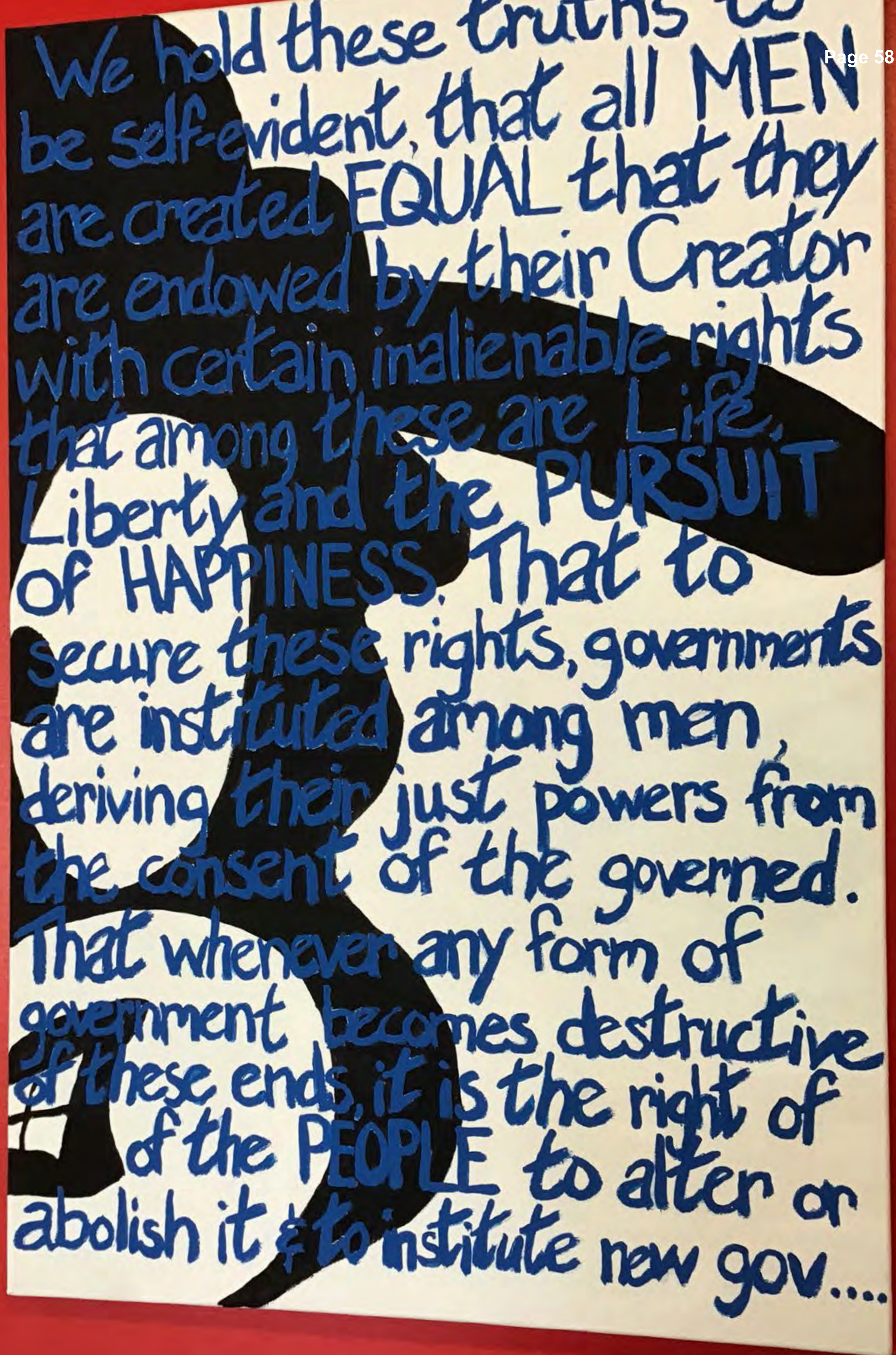
In 2019, New York City announced that it is the first city in the U.S. to meet the ambitious 90-90-90 HIV targets—93% of New Yorkers living with HIV know their HIV status, 90% of those with diagnosed HIV infection are receiving antiretroviral therapy, and 92% of those on treatment are virally suppressed.[135] Markedly improved HIV treatment outcomes, combined with rapid roll-out of PrEP and implementation of housing assistance and other structural interventions, have sharply lowered the rate of new HIV infections. From 2001 to 2017, the annual number of new HIV diagnoses declined across New York City by nearly two-thirds.[134] The decline in new HIV diagnoses has been especially pronounced for Black New Yorkers—from 3,097 in 2001 to 919 in 2017.[134]

New York City's experience is strikingly different from outcomes reported for the U.S. epidemic as a whole. As new HIV diagnoses plummet in New York City, they have remained stable nationally. New York's experience raises an obvious question: What can we learn from New York's experience in fighting HIV that can be applied in other jurisdictions?

Several characteristics distinguish New York City's approach. There has been strong political commitment at the state and local level to combat HIV in New York, as reflected by the courageous leadership of Gov. Mario Cuomo in outlining a blueprint for ending HIV in the Empire State.[136] New York City Mayor Bill DeBlasio has joined with the governor to provide energetic support for ending the epidemic. Communities have been engaged as key partners and leaders from the outset of planning to end New York's epidemic. New York ensures universal access to HIV treatment services, including for undocumented persons, and has undertaken energetic efforts to expand access to PrEP.

Another critical difference between New York and many other jurisdictions is New York's willingness to devote substantial state and local dollars towards fighting HIV. Due to significant state funding, New York has perhaps the country's most comprehensive AIDS Drug Assistance Program. State and local funding has also jumpstarted New York's pioneering effort to scale up PrEP. New York's Medicaid program is among the most expansive in the country, even though the federal share of Medicaid funding in New York is among the nation's lowest.[137] New York State and City have long used tax levy funding to support the community-based response to HIV. Unlike virtually all other jurisdictions in the U.S., New York City recognizes a legal right to emergency housing, and its plan for ending the HIV epidemic includes additional commitments to cover housing, transportation and nutritional assistance for all income-eligible people living with HIV.[136]

To replicate New York's successful push to end its HIV epidemic, we will need to persuade state and local policy-makers to prioritize efforts to end HIV and find ways to incentivize decision-makers to allocate state and local funding toward end-the-epidemic initiatives. It is clear, though, that substantial new federal funding will also be required to enable EHE jurisdictions to follow in New York's footsteps.


We hold these truths to
be self-evident, that all MEN
are created EQUAL that they
are endowed by their Creator
with certain inalienable rights
that among these are Life,
Liberty and the PURSUIT
of HAPPINESS. That to
secure these rights, governments
are instituted among men,
deriving their just powers from
the consent of the governed.
That whenever any form of
government becomes destructive
of these ends, it is the right of
of the PEOPLE to alter or
abolish it & to institute new gov....

contracts should be performance-based and include clear milestones toward self-sufficiency for Black-led organizations to lead efforts to end HIV. As the federal government's EHE plan envisions a key role for federally qualified health centers (FQHCs) in reaching the underserved and most vulnerable, focused efforts are required to expand and diversify FQHCs to include more smaller, minority-led organizations. Foundations should re-engage in the HIV response by prioritizing new funding for Black-led organizations and initiatives, and pharmaceutical and biotech companies should earmark a percentage of their profits for unrestricted funding to Black-led organizations and initiatives.

Focused investments are needed in Black leadership development across the breadth of the HIV response, with particular attention to investments in Black-led and Black-serving organizations. These investments should ensure that Black-led and Black-serving organizations are prepared to maximize their performance and improve their communities' HIV and broader health outcomes.[1331]

While grassroots energy and commitment will remain crucial to the Black response to HIV, it is essential to move beyond unpaid volunteerism as the backbone of much of the response, as a pipeline and pathway to real jobs and opportunities are essential to build the sustainable community infrastructure that will be needed.

Ensure that **EHE** efforts are responsive to the needs, circumstances and preferences of **Black** communities

All policy-makers, elected officials and communities must be educated and mobilized regarding EHE efforts, and specific and focused efforts must be undertaken to engage Black communities and elected officials in EHE planning and implementation. All organizations/agencies that receive federal EHE funding must have clear, meaningful mechanisms in place to obtain culturally responsive feedback from Black communities, and they must use the information obtained through these mechanisms to inform and guide service delivery.

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1. Under the Performance Imperative of the Leap of Reason Ambassadors Community, key criteria for social sector excellence include: (1) Courageous, adaptive executive and board leadership: (2) Disciplined, people-focused management; (3) Well-designed and well-implemented programs and strategies; (4) Financial health and sustainability; (5) A culture that values learning; (6) Internal monitoring for continuous improvement; and (7) External evaluation of mission effectiveness.

Leveraging Love to Expand Healthcare and Rights for Trans People

At a time of divisiveness and hatred in our country, one couple of Charlotte NC has found that love is a powerful tool for fighting transphobia and contributing to the prevention of HIV.

Alyson and Erick Jamison have been together as a couple of 10 years, becoming married four years ago. During their relationship, Alyson, who is living with HIV, began her transition. Over the last four years, Alyson changed her name and her gender identity marker, and received breast augmentation and gender reassignment surgery.

Throughout Alyson's transition, she has had the love and support of her husband. Indeed, Alyson's experience helped Erick become an energetic community advocate. "One of the biggest reasons I got into working in the community is because of my love for Alyson," Erick said. "I learned a lot about HIV, about stigma, and how stigma affects trans people, people over 50, and African Americans. Once Alyson decided she wanted to transition, I wanted to push myself to learn more about transitioning so I could help people.

"A lot of people know it's hard for the person who is transitioning but they think it's easy for the one who is not transitioning. But I had to change my whole mindset on a lot of things [after Alyson began transitioning]. It can affect you mentally, physically, sexually. The person who isn't transitioning wants to support their partner, but they also have to transition on their end as well. This is a struggle on both sides."

Alyson acknowledges that in many ways she has been blessed. Not only has she been able to rely on Erick's support, but she has also benefited from exceptionally supportive healthcare providers. "[My healthcare providers] just made me feel so at home," Alsyon said. "Every time I tell the nurse I need something, I've gotten it."

Alyson's healthcare providers have actively encouraged her work to educate and support other trans people in North Carolina. "When I work with other trans people, I try to get a feel for the person first," she said. "I encourage other trans people to keep going in life and I educate them on the experiences that I have had."

Alyson and Erick recognize that many trans people in North Carolina lack meaningful support. "I don't see many organizations providing support for trans people," Alyson said. "I can't say there are many organizations that people can turn to."

"Some organizations provide assistance to trans individuals but there is usually no one behind the desk who looks like [the trans person seeking services]," Erick notes. "There's typically no one who looks like African-American trans women or who understands their journey. Having that in place would make it a lot easier to retain people in care."

Many trans people in North Carolina avoid healthcare services out of fear of experiencing discrimination or judgmental attitudes. "Even before I went into care, I heard a lot of horror stories [about healthcare services for trans

people],” Alsyon said. “These horror stories keep people from going to seek care or getting the care they need. They don’t want to put themselves in situations that can harm them or make them uncomfortable.” Alyson said that the lack of trans-appropriate healthcare services in North Carolina is so acute that many trans women in the state have moved to New York to obtain the care and support they need.

As Alyson has devoted her time to supporting other trans people in North Carolina, Erick has contributed to the broader fight against HIV. Working as a prevention coordinator and case manager, Erick has educated people about HIV and linked people with needed services, including HIV testing, condoms, PrEP and counseling.

Across all of their giving back to their community, Alyson and Erick have been motivated by love. “We have a real love for LGBT youth and our broader community,” Alyson said. “We live in dangerous times, and I realize that the young people who are coming after us need education and support. I love that my husband’s love has pushed me to want to be out in the field with him more than ever.”

IN CLOSING

Toward Ending the HIV Epidemic: Implementing the We the People Vision and Framework

Now is the time to break the historical pattern of our national HIV response. Black America has been left behind at each step in the national response to HIV. But if we hope to end HIV, Black communities can't be left behind again. We can and we must do better as a nation.

We the People provides a blueprint to end our national HIV epidemic. Derived from clear scientific evidence and nearly 40 years of experience in fighting HIV, the approach outlined here is ambitious. Undoubtedly, it will strike some as daunting, and implementing it will inevitably encounter challenges and setbacks. But for a problem as serious, complex and multi-faceted as HIV, we cannot pretend that there are simple solutions. If as a country we truly want to make the HIV epidemic a thing of the past, we will need to tackle the many challenges that increase vulnerability to HIV and make it so difficult for many people to access and benefit from biomedical tools.

It is crystal-clear that if we hope to end HIV, Black America must drive this effort. No matter how critical government commitment and industry expertise are, hopes for ending HIV will founder without the energetic and well-resourced engagement and leadership of Black communities.

The *We the People* blueprint is beyond the means of any single organization to deliver. It is our hope that Black leaders, organizations, grassroots activists and diverse stakeholders use this blueprint to re-prioritize the fight against HIV and to determine how best they can contribute to ending the epidemic. For its part, the Black AIDS institute commits to reorient all of its work to galvanize action to implement this plan of action. And the Black AIDS Institute also commits to monitor and regularly report on progress in implementing this framework.

Now, all of us need to roll up our sleeves. No one can save us but us. We know what needs to be done. Let's do it.

Using Self-Love and Empowerment to Combat Homophobia

As a Black gay man living with HIV in Atlanta, Larry Scott-Walker long recognized the value of peer support in navigating a challenging social and healthcare environment. But after several efforts at organizing support groups for his peers, he kept noticing that these groups fizzled over time. By 2014, Scott-Walker and his colleagues realized that a new approach to peer support was needed.

This new approach manifested itself in the birth of THRIVE SS, which offers peer support without asking Black gay men to join traditional support groups. "We tried to usurp the stigma associated with traditional HIV support groups," Scott-Walker said. "We called our get-togethers a meet-up. It was on Saturday, and we had food and light cocktails and we just talked." Forty-five Black gay men living with HIV came to THRIVE SS's first meet-up, and 100 men were recruited online in the initiative's first month.

"A lot of efforts have focused on addressing stigma, but THRIVE SS had to figure out what the opposite of stigma is. A lot of traditional support groups centralize disease and stigma. We wanted instead to be positively positive. We wanted to challenge stigma and encourage self-love. I have permission to accept who I am, my HIV status included. I have the resiliency to deal with my HIV diagnosis. When we centralize love, we centralize the human being."

Scott-Walker and two other colleagues currently operate THRIVE SS, which has grown to more than 3,600 men nationally, including 945 men in Atlanta. About 300 Black women living with HIV receive support through a separate THRIVE initiative specifically designed for women.

THRIVE SS couples non-traditional meet-ups with in-person support, linkage to services, and a drop-in space. "THRIVE SS isn't just about feeling good but also about having what you need," according to Scott-Walker. "It doesn't take much to turn a person, especially a Black gay man living with HIV, off from care. You might love your doctor, but if the person at the front desk gave you attitude you might never come back. We try to love Black gay men back into care."

THRIVE SS forges working relationships with trusted public and private medical providers and mobilizes its brothers as peers to link people who are living with HIV but who are out of care with ongoing healthcare services. "With this approach, it doesn't feel like you are being linked by a medical professional. We track people over a year to make sure they have everything they need." THRIVE SS's peer workers are available to help at every step of healthcare delivery, including making an appointment or accompanying individuals to their appointment. Over the last year, THRIVE SS re-engaged and effectively linked to care more than 300 people living with HIV.

THRIVE SS's working partnerships with healthcare providers help improve the quality and acceptability of services available for Black gay men living with HIV. "We invite providers to quarterly events and report back to them the

feedback we have heard about their services. These are our brothers we are serving. We are gaining their trust, and we don't want the providers we work with to be part of the problem. We provide materials to help make clinics and other places more welcoming and affirming to Black gay men.

"I won't lie and say there are bunches of places in Atlanta that are Black gay male-affirming. There are lots of queer-affirming places that are not affirming for Black gay men. When we find providers who work well with Black gay men we prioritize them in our linkage."

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n-Person Advisory Meeting

Black AIDS Institute

Founded in 1999, the Black AIDS Institute (BAI) is the only uniquely and unapologetically Black HIV think and do tank in America. Powered by two decades of work to end the Black HIV epidemic and led by people who reflect the issues we prioritize, BAI grounds its work in Black leaders and communities across the country. Recognizing that health justice is a racial and social justice issue, BAI is deeply committed to exposing the systems and roots of oppression that marginalize Black people and exacerbate their health burden. Working to revolutionize the HIV response by centering Black experiences and perspectives, BAI aims to ensure that Black people are able to live their fullest, healthiest lives with dignity, care and respect.

Information Dissemination

The country's primary non-governmental source of information on HIV from a Black community perspective, BAI maintains a national network of more than 1,500 journalists, and its website generates more than 300 million online and print media impressions annually. BAI's regular online newsletter reaches thousands of subscribers across the country, educating them about key HIV-related scientific and policy developments. BAI also utilizes a rapid response alert system to educate and mobilize local partners about emerging threats and opportunities for action.

Mobilization and Advocacy

With 14 chapters and 12 affiliates across the country, the **Black Treatment Advocates Network (BTAN)** has emerged as BAI's central platform for mobilizing local Black communities to take action to increase access to HIV prevention and treatment services and to remove social and structural barriers that increase HIV vulnerability.

BTAN chapters are local coalitions composed of health departments, service providers, AIDS service organizations, community-based organizations, people living with HIV, and other stakeholders. Benefiting from annual three-day trainings and ongoing technical support from BAI, these BTAN chapters and affiliates are made up of well trained, highly motivated grassroots activists working in every region of the country to increase HIV healthcare access in Black communities, disseminate HIV-related scientific and policy information, and drive needed policy and programmatic change.

Through the **Black Women's Ambassador Program,** Black women advocates from across the U.S. and Puerto Rico use social media to advocate for, promote and educate other Black women about HIV treatment and prevention options. A response to the reality that Black women are almost 15 times more likely to be diagnosed with HIV than white women, the Ambassador Program has definitively demonstrated that Black women are not "hard to reach" and that their leadership is pivotal to ending HIV.

Cut the Stigma, a partnership between BAI and Lambda Legal, works to build a groundswell of public action to ensure elimination of counterproductive and scientifically groundless laws that criminalize HIV exposure, transmission or non-disclosure. In late 2019, Cut the Stigma launched a multi-stop tour to catalyze conversations on HIV criminalization with college-age students at the nation's historically Black colleges and universities.

Training and Capacity Building

For more than 20 years, BAI has provided training and technical assistance to build the capacity of health departments, community-based organizations, health care organizations, and AIDS-service organizations to effectively address the HIV-related needs of Black Americans. Technical topics addressed by BAI's training and capacity-building work include science and treatment knowledge, current research updates, PrEP learning collaboratives, cultural humility, race and equity, and social determinants of health. Technical assistance by BAI supported the opening of the first public sector PrEP clinic in the South (specifically designed to increase PrEP access in Black communities) and creation of a unified PrEP referral system in Houston.

Each year, BAI trains more than 400 BTAN grassroots advocates and provides technical support to numerous state and local health departments. Using approaches tailored to each setting's needs and circumstances, BAI aids health departments in forming planning bodies, task forces and working groups focused on particular issue, with the aim of building the capacity of state and local health leaders to engage Black communities as essential partners in their HIV response.

Policy

BAI serves as a trusted, authoritative voice interpreting important HIV-related policy issues. Annual reports on the State of AIDS in Black America have provided up-to-date information and policy recommendations on a range of key issues, including PrEP, HIV testing, and improving outcomes along the HIV continuum of care. In 2018, as Congress considered proposals to gut the Affordable Care Act, BAI produced the only major report analyzing the impact that such proposals would have, if enacted, on Black people. These reports are regularly relied on by grassroots advocates, community leaders, members of Congress and other elected representatives, the news media, and health officials at the federal, state and local levels to inform and guide their efforts to address the HIV-related needs of Black communities.

Direct Prevention and Treatment Services in Los Angeles

Although national in its scope, BAI prioritizes contributing to the HIV response in its headquarters home of Los Angeles. BAI began direct provision of HIV testing, prevention and linkage-to-care services in Los Angeles in 2015, and these services have rapidly expanded over time.

At **A Clinic for Us,** BAI provides free, fast and confidential HIV testing to more than 2,500 people annually in our Los Angeles office, accepting both appointments and walk-ins. Persons who test HIV-positive or are in need of follow-up prevention services benefit from BAI's client navigation and linkage-to-care services, including primary care services available through BAI's partnership with St. John's Well Child and Family Center in South Central Los Angeles. Each year, BAI links 400 HIV-negative people to PrEP services.

Revolution in Color is a group of programs that empower young Black queer folk in Los Angeles. These include a core program focused on personal goal setting, life skills and events to mobilize young Black queer people to build positive connections and have healthy sex and relationships; monthly discussion groups; a peer mentor program; and training to build the leadership skills of young Black gay and bisexual men to promote sexual health in their communities..

PROFILES IN BLACK EXCELLENCE

Promoting Black-Serving and Black-Led Community Organizations

The environment for Black-serving and Black-led HIV organizations continues to evolve. Under the federal government's plan for ending the HIV epidemic, new funding will soon become available to support HIV services in targeted counties and states. Yet, the degree to which Black-serving and Black-led organizations will benefit from this new funding remains unclear, especially for smaller organizations that lack the infrastructure to compete effectively for new resources.

And the long-term future is even more fraught for community organizations. "With multi-year [end-the-epidemic] grants you can build infrastructure but what happens after [the deadline for ending the epidemic in 2030]?" asks Gabriel Maldonado, CEO of TruEvolution, a non-profit organization in southern California dedicated to LGBTQ justice and HIV prevention. "We are concerned with the longevity of our being seen as an HIV organization, with large portions of our funding dependent on grants and grant renewal processes."

The quest for sustainability for Black/Latinx-serving and Black/Latinx-led organizations led to the creation of The Gathering, a quarterly series of convenings designed to organize, mobilize and capture the priorities of such organizations within the federal initiative to end the HIV epidemic. Conveners of The Gathering include TruEvolution, My Brother's Keeper (Mississippi) and Abounding Prosperity (Texas). The Gathering aims to develop and drive key recommendations for funding under the federal EHE initiative, establish and secure an ongoing mechanism for community organizations to bill for services in a manner that is not tied to grant funding, and identify and secure support for advocacy and organization-building services.

Under the umbrella of The Gathering, 22 organizations have completed surveys designed to elicit information and perspectives regarding sustainability, capacity and resourcing needs from diverse Black/Latinx-serving and Black/Latinx-led organizations. The Gathering is expressly designed for service providers rather than advocacy organizations.

"When requests for proposals for end-the-epidemic activities are released, minority organizations of all sizes and scopes want to know that they have a seat at the table and a chance to use this funding for sustainability," Maldonado said. "We are requesting that CDC and the [Health Resources & Services Administration] to carve out 30% of their [EHE] funding for community-based organizations."

The Gathering has already held two meetings, developed a digital platform to facilitate information sharing, and created a governance structure for the quarterly meetings. One key anticipated outcome of this initiative is the eventual convening of a meeting with non-HIV-specific funders to explore strategies for supporting the long-term sustainability of community organizations created primarily to respond to HIV in Black and Latinx communities.

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BLACK
SOUTH
RISING

The Future is Now!

A Political Agenda for Advancing, Building, and Sustaining Black HIV Leadership in the South

INTRODUCTION

The path to ending the South's HIV epidemic should elevate, nurture, and provide Black leadership and organizations resources. While this paper focuses on HIV, we must remember that HIV is a symptom of what is ailing the health of black people. We must look at the root causes, structural factors, social determinants of health, and trauma to *End the HIV Epidemic*. Shifting the Southern HIV epidemic approach will facilitate true freedom and liberation for black people - collectively and individually. The crises of our present time should not and need not be our future; therefore, we seek to create a new narrative and legacy. This new narrative is reflective of our values of self-determination, equality, equity, empathy, freedom, liberation, innovation, collective action, and community.

Despite the strength and resiliency -- the ability to overcome life's challenges – of black people, the level of social and health disparities that have plagued this community is no longer acceptable. Black people represent 13% of the U.S. population. Still, we also represent 50% of all persons living with HIV, 46% of incarcerated individuals, and the criminal justice (injustice) system, 40% of the homeless population, and now there is higher exposure, infection, and death from Covid-19 among black people. These gloomy statistics result from overwhelming systemic and structural inequities arising out of historical racism and discrimination and are further exacerbated by the unacknowledged and unresolved trauma resulting from historical and current events.

The provision of funding, while helpful, is not the only answer. For example, government agencies charged with ending the HIV epidemic have received billions of dollars, and organizations charged with providing vitally needed services have received millions of dollars. However, this forty (40) year effort has failed to reduce the level of HIV in the Black community significantly. Black people are exhausted. Black people are sick. Black people are dying.

The systemic racism toward Black people has undermined our ability to advance and prosper in a nation with an abundance of capital and expertise, which cannot continue. The existing narrative must change. The approach, strategies, and efforts must evolve to effectively address HIV, poverty, poor health, mass incarceration, and justice for the murders of Black men, women, and children by the police (public servants who are supposed to serve and protect). It is time to move from talking to action, from incremental change to full change, and from complacency to standing firm in the face of white backlash. There is a tremendous responsibility not only to say something but also to respond to injustices that continue to be perpetrated on black people and our communities. This document, the "Future Is Now! A Political Agenda for Advancing, Building, and Sustaining Black HIV Leadership in the South" will provide Black leaders with a framework for educating the community and decision-makers working in the South. Additionally, Black South Rising hopes this political agenda will lead to the engagement of Black people and other stakeholders in movement building, mobilization, and advocacy to end the HIV epidemic and other intersectional challenges facing Black communities in the South.

APPROACH: THE FUTURE IS NOW!

“The strongest people in the world are not those most protected: They are the ones who must struggle against adversity and obstacles and surmount them to survive.”
Author and Date Unknown

“We have risen. We know what we must do to secure our rights as human beings and citizens of this Country, and we will resist every attempt from those who seek to deny us.”
Black South Rising, 2020

Black South Rising, in honor of our ancestors and present leaders of the Black Southern HIV movement, whose shoulders we stand on, has created a political agenda or plan that addresses the moment -- today -- and not tomorrow or some distant future. This political agenda addresses the current political, social, and public health crises -- racism, voter suppression, HIV, and Covid-19 -- destabilizing and devastating Black communities in the South. Despite these grave challenges, we remain determined and hopeful. We rely on our resilient spirit and generosity that have enabled us to survive centuries of slavery, systemic oppression, and stigmatization to become a mighty people of varied social, cultural, political, and economic expressions.

The current anti-black rhetoric and policy choices that threaten Black people in the U.S. are not new. Despite the centuries of racial precedent that have denied Black people their human and civil rights, we have been instrumental in building this Country, fighting its wars, and paying taxes. Leading the way to secure our civil rights was the Black South. The Black South still comprises the largest group of Black people -- African Americans -- in the United States. It was predominately in the South that our Black freedom fighters waged non-violent battles to end Jim Crow, obtain our civil rights, and led the advances for political, economic, and cultural power -- advances which have made the South a mecca for young Blacks and Blacks returning to the South seeking life within culturally and socially relevant environment.

Yet, this country continues to treat us as "three-fifths” of a person, as referenced from a compromise reached among state delegates during the 1787 United States Constitutional Convention. In 2020, Black people in America do not have the same right to life in terms of controlling and protecting our bodies, the same right to viable opportunities for economic advancement, or the same right to create safe spaces to fully experience “life, liberty, and the pursuit of happiness." This political agenda acknowledges this country's deep-seated racism, anti-blackness, and the legacy of over 250 years of dehumanizing slavery, followed by more than 150 years of domestic terrorism and systemic discrimination. The continuation of government-sanctioned violence on our bodies, our communities, and the environment in which we live today leaves us with disproportionate levels of trauma, illness, and death.

This political agenda addresses this legacy and its attuning consequences. Instead of seeking to work within existing systems and structures that protect white privilege and power, we will build upon the following three demands to develop, promote and safeguard emerging systems and organizations led by Black people.

1. First, multi-year investment in funding and non-monetary resources from foundations and corporations must be made in support of Black leaders, and organizations must address the aforementioned societal ills and wrongs..

2. Second, these resources must be used to:
   a. Confer with Black southern elected officials, representatives and key staff members from the Congressional Black Caucus, and Congressional HIV and AIDS Caucus, and leaders from other Black coalition efforts to create a staffed commission (or think tank) organized for interdisciplinary research and to develop innovative systems and programs that are culturally specific to the Black experience in America. Black government officials will be invited as guest presenters to provide data and status reports on upcoming initiatives.
   b. Confer with funders to provide financial support to Black leaders who work in the South so they can fully participate in the creation and management of this commission or pursue other opportunities that will influence the work of the commission, e.g., fellowships to study specific areas or sabbaticals to learn or enhance knowledge and skills to put into practice.

3. Third, systems and organizations exhibiting racism and bias -- intended or unintended -- must change or be defunded.

Our grit, determination, and faith have enabled Black people to overcome tremendous odds against our ongoing survival. These demands and the following change initiatives are critical to creating lasting, sustainable change and growth for our lives and future generations of Black people and to ultimately end the HIV epidemic in the South. Our ongoing resiliency as a people is a powerful antidote to oppression. We shall not be moved.

AGENDA: CHANGE INITIATIVES

Using an intersectional analysis, we must challenge anti-blackness, systemic racism, and poor social determinants of health, making us vulnerable to HIV and other deadly health viruses such as Covid-19. The Black community requires a comprehensive response -- *change initiatives steeped in racial and social justice* -- developed and led by black people that address the underlying conditions that facilitate HIV transmission.

HIV, combined with racism, stigma, economic inequity, fear, and mistrust of medical health systems, has had an outsized destabilizing and devastating impact on Black communities in the South, which has caused a decline in hope, trust in public health, and mutual respect. The change initiatives listed below strive to disrupt and correct the political, social, and environmental factors that lead to confinement, illness, disability, and premature death of black people.

While it is clear that the United States is far from addressing the lasting impacts of historic and continuing injustices, we must insist that the following changes occur without further delay.

We insist on Black leadership and representation. We must prevent non-Black institutions, organizations, or individuals from blocking Black people from acting in their own best interests. As people of African descent, we are naturally spiritual and creative. As a result, we are intuitive, and from our many lessons on how non-Black people use power, we are keenly aware when the weather is changing. Just as an individual with a knee injury knows when it will rain, so do black people know when someone is acting out of their racism and bias. We will no longer accept other people's definitions of racism or prejudice. We will no longer debate or argue with non-Blacks about the state of affairs in the Black community.

The importance of this imperative cannot be overstated. Overall, we are generally not involved in the design and implementation of services for our communities. For the most part, the delivery services by non-Black people would be acceptable; however, many are -- aware or unaware -- of organizational and individual racial biases and anti-Black attitudes and behaviors. There is zero to little accountability to black people by these organizations or individuals. Our repeated insistence on meaningful involvement has no sway or credence with the majority of these organizations.

Our approach will require the adaptation of organizational leadership and structural models that suit and meet the Black community's needs. Such an approach will require funders to think outside their comfort zone of what they think will work -- outputs and outcomes -- which does not bear any actual relationship to the actual malice and negligence suffered by Black people in this Country. If funders want to see real change and progress, they must courageously fund black-led organizations to do the work that no one else can do by supporting:

- *Innovation.* Innovation, which requires the opportunity to reflect and dream deeply, is a necessity. Many of the existing services are stale, outdated, and have few cultural reference points for Black people who may use them. Furthermore, how organizations carry out their mission and services must be rethought. Our survival goes beyond the standard working hours of 9 to 5. Supporting innovation would enable Black people to build organizations, services, and interventions that embody our cultural expressions in a manner that would naturally attract our people. Resources are needed to figure out how to make these dreams of innovation a reality.

- *Safe spaces.* Safe spaces where Black people can be free are desperately needed. To many, our existence is a "no," which we have internalized. We must combat this internal "no" by providing spaces that allow people to express themselves for who they are.

We insist on human rights and social justice. The clarion call of "Black Lives Matter" requires us to protect every individual who identifies as Black in this nation regardless of race, gender identity, sexual orientation, age, immigration status, or class. We live not in one single world but a multi-diverse world, so we need multiple approaches and spaces. In other words, liberation comes in many forms. This rethinking of how we move through this world will require us to reimagine and reorganize our society. It begins with the call to stop shaming our people. While we must also strive for personal responsibility and accountability, we cannot do so in a manner that shames people. We cannot legislate attitudes and behaviors, but we can educate."Black Lives Matter" requires us to go beyond who we say is black for black people are not homogeneous - we, of the African diaspora, experience the same anti-blackness, racial bias, gender inequities, homophobia, and transphobia. People must have options to grow, to succeed, or to fail on their own.

We insist on the divestment and dismantling of destructive systems and institutions. HIV is also a moral issue and represents our moral failure as a nation that is rich in resources and expertise to stop the damage and carnage caused by social and public health crises. Ending the HIV epidemic by tackling multiple levels of stigma, criminalization, and dismantling systems are possible, but only if Black leaders have the external and internal resources to do this work and find the best platform for their work. Racial equity means that organizational leadership in the region must reflect communities most impacted. We insist upon a commitment to create and sustain new Black-led organizations and adequately support existing Black-led organizations. Once again, as referenced one of the three previously stated demands, we insist that systems and organizations exhibiting racism and bias -- intended or unintended -- must change or be defunded.

We insist on funders changing how they resource community projects, programs, and interventions. We must challenge the unwillingness of funders to change how they do business. Donors must accept that funding should be community-driven, particularly in the South, which should be treated differently from other regions across the nation due to its peculiar circumstances. Donors should be aware that existing organizational structures have neutralized Black leaders' power and impact their ability to advance policies and programs. These changes will address the lack of options for services within the community. We must look beyond the large organizations in the field to the Black leaders who stand shoulder to shoulder to fight for our people and our communities. Funders must understand that we have the capacity, skillset, and expertise to address and resolve our community's issues. But we do not have the funding. These resources are needed to support our movement building through messaging, mobilization, and remembrance. Thus, fighting for funding flexibility will enable Black organizations to serve the whole person and not be restricted in delivering services.

Finally, funders must use their influence to promote Black leadership -- at the senior and executive management level, at the board of directors' level, and within the county and state health departments. Furthermore, we must ensure that Blacks living with HIV are afforded the opportunities to fully participate as subject matter experts, whether in organizations or at decision-making tables. We ask organizations that work in the South to re-examine their boards and staff and take steps to change if it is not reflective of Black leadership. Organizations cannot understand our needs and have our best interests at heart if we are not included at every decision-making level.

We insist on implementing workable solutions to address root causes, e.g., social determinants of health*, *that elevate HIV vulnerability and risk.

- *A right to a livable wage or universal basic income*. We must insist on adequate compensation for work performed. After rent/mortgage, utilities, transportation to and from work, food, phone bill, one is working to survive barely. We must ask ourselves, how is one able to live comfortably or find any comfort at all? It is cruel and unusual punishment to ask people to work for low wages. People sometimes give up not because they lost hope, but because they realize they never had an actual fair opportunity to succeed. They look at the system as being rigged.

- *A right to affordable, quality, and safe housing.* We insist on removing state-sponsored segregation laws, regulations, practices, and traditions, which impedes affordable and safe housing. A ponderance of evidence exists that proves that housing stability, quality, safety, and affordability all affect health outcomes. The HIV community has long advocated for housing as treatment. This is no more evident in looking at housing and Covid-19. People inadequately housed or without accommodation are especially vulnerable to poor health and infectious diseases, including COVID-19. We must insist that people in shared living spaces with multi-generations of family members or individuals, and people who are confined in institutions such as long-term nursing homes, substance use recovery houses, prisons are equally protected from infectious diseases and premature death.

- *A right to affordable, quality healthcare*. Until legislation for universal health care or a one-payer system -- Medicaid for all -- is passed and enacted in this Country, we insist that Southern states that have not pass legislation allowing for Medicaid Expansion do so immediately. At present, the Affordable Care Act provides provision which enables governments to enact Medicaid Expansion to ensure that working-class and poor people can access the healthcare system.

- *A right to control our bodies from nonconsensual research, medical experimentation, and maltreatment*. Starting with the harm perpetrated on Black people, the medical community must understand that the environment they created has to be addressed to get Black people to trust and re-engage with them. Therefore, the medical establishment must acknowledge the harm and trauma caused by medical mistreatment and maltreatment.

- *A right not to be criminalized for behavior based on health conditions or economic survival*. We insist that criminal justice reform -- changes in policing, mass incarceration, and systematic racism - also include HIV criminalization. There exists no scientific evidence that laws criminalizing non-disclosure, perceived or potential exposure, or transmission have any public health benefit. These laws may discourage HIV testing, treatment, and disclosure of HIV positive status.
  We also advocate against the criminalization of sex work and substance use. In terms of sex work, We must educate our community about sex work and the difference between sex work vs. sex trafficking to prevent the criminalization of consensual sex work. Consensual sex work can be defined as one's chosen profession or one's means of economic survival. In terms of substance use, we must educate the community that the further criminalization of drug use does not address the underlying issue of trauma born of mistreatment or neglect. Substance use can be viewed as an adaptive coping mechanism. For example, Black people suffer from higher rates of societal and personal trauma in the general population. Research and lived experiences indicate that trauma as substance use often goes hand-in-hand. Therefore, we support efforts to decriminalize substance use, starting with Congress' efforts to legalize marijuana.

- *A right to be free from an unjust criminal justice system*. We insist that there be reform of both the adult and juvenile criminal justice systems. These reforms should focus on phasing out the use of private prisons; creating sentence parity for individuals convicted of non-violent drug offenses to eliminate the sentencing disparities between racial and ethnic population groups; providing guidance on addressing abuses within our criminal justice facilities and probation and parole systems; and discontinuing forfeiture laws. We further insist on policing changes that hold police officers accountable for the loss of life due to the use of excessive and deadly force on unarmed Black men, women, and children.

- *A right to comprehensive sex education*. Comprehensive sex education based on human rights is required to support Black people across the life span. This information is vitally important when making decisions about one's sexual and reproductive health. When this information is unavailable, people end up being vulnerable to sexual coercion, sexually transmitted diseases including HIV, and unintended pregnancy.

- *A right to cultural expression and creativity*. As stated by the United Nations' Article 27 of the Declaration of Human Rights, "all individuals have the right to enjoy and make use of cultural heritage and cultural expressions." As stated earlier, Black people are more likely to engage with service providers when they can see some semblance of themselves in cultural affirmations. Furthermore, our cultural heritage and expressions in storytelling – oral and written, the creative arts, and other cultural indicators serve to validate and sustain our identity and preserve our dignity.

We insist on accountability. We want change, but we, too, have a responsibility and accountability for making this change happen in light of a social contract that has gone beyond fraying at the edges and is shredding right before our eyes. Therefore, organizations must be willing to rise above mere charitable activity, engage in aggressive advocacy for society's outcasts, insist on a more equitable distribution of wealth and power, and provide checks and balances against overbearing corporations and governments. Nonprofit leaders must possess "vision, courage, accountability, ethics and competence," plus a willingness to put aside particular institutional missions to join coalitions working for the broader public interest. In other words, we also must confront the inherent tension between service and advocacy and move service providers from focusing solely on behavioral change to include advocacy. They must advocate for racial justice, social justice, and human rights. We know what needs to be done. It’s just in the hustle and bustle to survive that we forget. However, we have a history of black advocacy throughout this epidemic that enables us to stand on tradition and move forward.

Yet, Black leadership also has a responsibility and must be concerned with our privilege, causing us to inadvertently or deliberately act as gatekeepers around resources and issues of importance to the black community. We have solutions that can shift how people work and how we hold each other accountable. We can also build our systems beyond the existing structural systems which reinforce white racism, bias, and privilege.

BACKGROUND

Black South Rising is a collective of advocates, community and organizational leaders, and black people living with HIV. Black South Rising aims to work in the South to raise Black HIV movement leaders' visibility. As Black HIV advocates doing movement work in the United States South, we recognize the urgency and necessity of reframing the narrative around addressing the epidemic. The history of slavery, Jim Crow, and racial violence and the present-day horrors have shaped our current political moment in ways that exacerbate HIV that overwhelmingly impacts our lives. However, our history is not only one of horror. Our ancestors' courage inspires us as we stand on their shoulders in this fight. We are demanding a renewed commitment rooted in a Black cultural lens addressing HIV in the South.

We recognize the urgency and necessity of reframing the narrative around addressing the epidemic in our region. We are clear that Black people should lead the conversation about HIV in the South. Any discussion around HIV in the South that does not center the voices of Black people is a failed enterprise from the start. We will call out and seek redress from organizations that do not adhere to this demand of action.

Purpose. The purpose of this project was to a) gather information from Black HIV advocates and individuals doing HIV work in the South, b) better serve black people who may be at risk for, vulnerable to, or living with HIV, and c) better support movement-building efforts that can inform our HIV advocacy agenda. Specifically, we wanted to understand what exists and what is working in terms of leadership, advocacy, service issues, which may reduce existing HIV-related health disparities. This document represents the results of Black South Rising's community engagement effort, as described below in the methodology section.

Methodology. Black South Rising (BSR) sought the meaningful involvement of Black people residing in the South impacted by HIV. To this end, Black South Rising conducted and collected responses from an online survey of 100 and conducted in-depth interviews with eight HIV movement and organizational leaders. The data from these two activities was used to draft this political agenda. The draft document was then reviewed by a focus group of 8 individuals and the Black South Rising Workgroup members. The feedback from both groups was incorporated into this document.

BLACK SOUTH RISING WORKGROUP MEMBERS

In alphabetical order: Maximillian Boykin, Linda Dixon, Dennis Hardy, Vanessa Johnson, Johnny Ray Kornegay III, Leisha McKinley-Beach, Venita Ray, and Charles Stephens.

THANK YOU

We thank the Black leaders and constituency who joined us on this journey to advance, build and sustain Black HIV leadership. Your feedback in the form of survey response, interviews, comments, and support for the initial Black South Rising statement was constructive and will enable us to move forward together.

DEMANDING BETTER:

An HIV Federal Policy Agenda by People Living with HIV

ACKNOWLEDGMENTS

This document was a collaborative effort informed by our relationships with thousands of people living with HIV throughout the United States, as well as our lived experience.

Authors contributed thought leadership as well as writing, research, reflection, and editing time. We are grateful to Martha Cameron, Barb Cardell, Marco Castro-Bojorquez, Cecilia Chung, Tami Haught, Vanessa Johnson, Ronald Johnson, Naina Khanna, Kamaria Laffrey, Lorenzo Lewis, Mark Misrok, Heather O'Connor, Venita Ray, Malcolm Reid, Bamby Salcedo, Linda Scruggs, Waheedah Shabazz-El, Andrew Spieldenner, Kiara St. James, Sean Strub, and Evany Turk for their contributions.

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We dedicate this agenda to the many people living with HIV who paved the way for our understanding of HIV as an issue of justice, and on whose shoulders we stand. Some are still with us and too many have been lost along the way.

May this collective set of priorities, created jointly by U.S. based networks of people living with HIV for the first time ever, assure a better world for all of us.

For Mary. For Marco. For Deloris. For Loren. For Juanita.

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

ICW North America

NATIONAL WORKING POSITIVE COALITION

Positively Trans

POSITIVE WOMEN'S NETWORK USA
pwn-usa.org

THE REUNION PROJECT

SERO

THRIVE SS

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EXECUTIVE SUMMARY

Networks of people living with HIV in the United States have come together as the U.S. People Living with HIV Caucus (HIV Caucus) to outline our policy agenda for the federal response to the HIV epidemic. People living with HIV networks are organized formations created, led by, and accountable to the estimated 1.1 million people living with HIV in the United States. They are vehicles through which we, as people living with HIV, can define our own agenda, choose our own leaders, and speak with collective voices.

For stakeholders in the federal government, the HIV Caucus brings a unique lens, informed by lived experience, to the development of policies to ensure better care, treatment, and quality of life for people living with HIV. The networks which make up the HIV Caucus have been involved as service providers, have run programs that serve people living with HIV, and have built community-based organizations and advocacy initiatives from the ground up. We are in direct contact with tens of thousands of people living with HIV throughout the United States.

These unique abilities and access inform our work and led us to create this living policy agenda to collect our expertise into a road map for lawmakers and other key stakeholders to use in addressing the HIV epidemic at the federal level.

This policy agenda contains recommendations in 5 issues areas which must be centered in every aspect of the federal HIV response:

1. **Concretely elevating the meaningful involvement of people living with HIV and disproportionately impacted communities in the HIV response;**
2. **Proactively creating an affirming human rights environment for people living with HIV by addressing stigma, eliminating HIV criminalization, and halting molecular HIV surveillance;**
3. **Addressing inequities in the federal response by attending to racial and gender disparities;**
4. **Adding sex workers and immigrants living with HIV as priority populations throughout the federal response; and**
5. **Affirmatively committing to improving quality of life for people living with HIV.**

To address each of these issue areas, we have suggested concrete recommendations for the associated executive agencies, the HIV National Strategic Plan, and the Ending the HIV Epidemic Plan, which are broadly delineated on the pages that follow.

Concretely elevating the meaningful involvement of people living with HIV and disproportionately impacted communities in the HIV response
Staff federal bodies addressing the epidemic, such as the Office of National AIDS Policy, with people living with HIV from the communities most impacted by the epidemic and recharter the HIV advisory boards of the federal agencies to include a minimum of two seats for representatives of the HIV Caucus.
Develop a process to solicit input from, engage and consult with the HIV Caucus, and include meaningful involvement of people living with HIV indicators in the final version of the HIV National Strategic Plan and in updates to the Ending the HIV Epidemic Plan.
Proactively creating an affirming human rights environment for people living with HIV
Identify stigma-reduction activities that partners in the HIV response can engage in, require Ending the Epidemics jurisdictions to create plans that incorporate these activities, and resource people living with HIV networks to develop and implement stigma-reduction initiatives.
Utilize data collection tools and interventions that examine structural change.
Promote advocacy efforts to remove punitive laws and policies, like HIV criminalization, by acknowledging the federal government's role in creating them and making clear commitments in federal plans to end HIV criminalization.
Declare a moratorium on molecular HIV surveillance and partner with people living with HIV networks to develop standards for obtaining informed consent; privacy protections; and security, sharing, and storage protocols.
Implement community generated standards in all aspects of the federal HIV response and ensure funding is in place for training and compliance.
Addressing inequities in the federal response: attend to racial and gender disparities
Explicitly include racial and gender disparities as elements of the HIV epidemic to be addressed in all funding opportunities and create grant opportunities for and led by these populations.
Require Ending the Epidemic jurisdictions to target resources to Black, Indigenous, and other people of color, especially those who are also gay and bisexual men, people of trans experience, people who use drugs, sex workers, and immigrants.
Require jurisdictions and grantees to provide care services to dependents while people living with HIV receive services and to screen for intimate partner violence.
Adding sex workers and immigrants living with HIV as priority populations throughout the federal response
Push to prohibit the practice of using condom possession as evidence of sex work and eliminate federal policies conflating sex work and human trafficking.
Prioritize and require commitments to the decriminalization of sex work, including restrictions of individuals with sex work-related or drug-related convictions from accessing federal programs and services.
Ensure health care is accessible regardless of immigration status.
Add sex workers and immigrants as priority populations in the federal HIV response and fund programs led by and serving them accordingly.
Fund language services, particularly those that are in-person, and require certain grantees to staff certified medical interpreters or train staff on interpretation utilization.
Affirmatively commit to improve quality of life for people living with HIV
Create a minimum standard of care and quality of life for people living with HIV, promulgate regulations requiring those providing health care to people living with HIV to conform to those standards, and monitor and report how these standards are being upheld.

Establish access to online and in-person benefits counseling/advisement for people living with HIV; design system to improve portability of benefits between jurisdictions; and create programs to train, recruit, and hire people living with HIV into the HIV workforce and other employment opportunities.
Fully fund Housing Opportunities for People with AIDS and other federal housing programs and enforce the Fair Housing Act to address housing discrimination.
Require the federal HIV programs to track and address housing for people living with HIV.
Improve the Supplemental Nutrition Assistance Program to account for regional differences, increase overall benefits, continue extensions of work requirements, and reduce administrative burdens for people living with HIV.
Improve, expand, and fund access to sexual and reproductive health care for people living with HIV, including transition-related care, and monitor this progress with metrics in the federal HIV response.
Fund research and create accessible guidelines for birthing people living with HIV to breast/chest-feed their children that do not include criminalization.

US PLHIV CAUCUS

DEMANDING BETTER:

An HIV Federal Policy Agenda by People Living with HIV

BACKGROUND

About Us

We are networks of people living with HIV (PLHIV networks) in the United States. PLHIV networks are organized formations created, led by, and accountable to the estimated 1.1 million people living with HIV (PLHIV) in the United States. PLHIV networks are vehicles through which we, as PLHIV, can define our own agenda, choose our own leaders, and speak with a collective voice.

Our networks represent communities most impacted by the epidemic in the United States: Black gay and bisexual men living with HIV in the U.S. South, Black cisgender and transgender women living with HIV, transgender women of color living with HIV, Latinx people living with HIV, survivors of HIV criminalization, and people aging with HIV. Our constituencies are diverse – including groups organized around race, gender, age, gender identity, sexual orientation, and immigration status – and we work across coalitions and communities on issues that impact us.

PLHIV networks bring a unique lens, informed by lived experience, to the development of policies to ensure better care, access to treatment, and quality of life for PLHIV. As PLHIV, we understand HIV-related stigma, discrimination, and structural conditions -- including racism, homophobia, sexism, transphobia, xenophobia, ableism, and poverty -- in direct, embodied ways. Many of us have been involved as service providers, have developed and led programs that serve PLHIV, and have built community-based organizations (CBOs) and advocacy initiatives from the ground up. We are in direct contact with tens of thousands of PLHIV throughout the United States and are consequently able to identify and, where resources allow, respond to emerging trends quickly.

There is a marked difference between collaborating with or taking input from individual PLHIV and engaging with organized formations of PLHIV. Processes to take input from or consult with individuals living with HIV generally have no available mechanisms for, nor resources to support, community accountability. Nor do they provide real avenues to support engagement by PLHIV representing the communities most affected by HIV, who may be facing various barriers that circumscribe their ability to effectively participate in decision-making or advisory processes. Thus, working with individual PLHIV is frequently tokenizing and disempowering to PLHIV and reinforces the inequities in race, gender, and class that have framed dominant discourse and policymaking on the HIV epidemic to date.

The United States People Living with HIV Caucus (HIV Caucus) emerged in 2010 from the need for a national voice for PLHIV. The HIV Caucus is composed of members Global Network of People Living with AIDS -- North America, International Community of Women with HIV/AIDS -- North America, National Working Positive Coalition, Positively Trans, Positive Women's Network-USA (PWN), Reunion Project, SERO Project, and THRIVE SS. As a national "network of networks," the HIV Caucus has taken the lead on several issues that PLHIV face, including addressing national HIV plans and policies that affect us.[1] The HIV Caucus has been a coordinating partner with AIDS United and Treatment Access Expansion Project at AIDSWatch, the national HIV advocacy day, bringing together hundreds of PLHIV and allies from around the country each year in Washington, D.C., to engage legislators and federal agencies.

It is long past time for national leadership on HIV to make this shift towards formally recognizing PLHIV networks as necessary partners to help organize, inform, and implement the federal domestic response. Put simply, you cannot end the HIV epidemic without us. This is no longer a demand – it is an absolute imperative. It is in this spirit of partnership that we bring the below analysis of the current federal response and our recommendations forward.

Contextualizing the Federal Response to the United States HIV Epidemic

The federal response to the domestic HIV epidemic is situated within a larger context of politics and culture, including sex negativity, HIV-related stigma, racism, homophobia, transphobia, sexism, classism, and the criminalization of poverty. As a result, since the first cases of AIDS were reported 40 years ago, and while health care providers, clinicians, and community advocates organized to develop compassionate approaches, the political response itself has been plagued by an overall lack of will to actively value, invest in, and affirm the lives of those communities most impacted by the domestic HIV epidemic -- the same communities our networks represent.

For nearly 30 years, the U.S. did not have a comprehensive, national plan to address the HIV/AIDS epidemic. Critical programs and policies to provide health care and treatment to PLHIV, especially the Ryan White HIV/AIDS Program, and various initiatives to prevent HIV funded by the Centers for Disease Control and Prevention (CDC), collectively formed a patchwork response to the domestic epidemic. This fragmented approach to HIV was ironic given that the U.S. engaged with other countries to develop their annual national plans (known as Country Operational Plans, or COPs) as a required component of the funding process under the President's Emergency Plan for AIDS Relief (PEPFAR), established in 2003[2]. However, it was also inevitable – prior to the adoption and enactment of the Patient Protection and Affordable Care Act (ACA), health insurers were legally permitted to discriminate against people with pre-existing conditions[3], such that PLHIV in the U.S. were not generally eligible for private or employer-sponsored health insurance coverage[4], and relied on a medley of social and health related services to fill in the gaps.

In the mid-2000s, as early data began to show that viral suppression in PLHIV would reduce the likelihood of onward HIV transmission, epidemiologists began making the case that any successful plan to "end the HIV epidemic" would have to rest on a foundation of two primary bedrocks:

1. Aggressive HIV testing to identify new diagnoses and
2. Medical treatment to suppress the viral loads of those living with HIV.

This became known as the "test and treat" model. Some advocates pushed to expand the model's frame first to "testing, linkage, and care" (TLC), then to TLC+, in a discursive recognition that successfully implementing widespread and early HIV treatment for those who receive a positive diagnosis requires first that people living with HIV are in medical care and that they were likely to need other services and support in order to facilitate access to that medical care.[5]

The United States National HIV/AIDS Strategy: 2010-2020

The Obama administration's release of a 2010-2015 National HIV/AIDS Strategy for the United States (NHAS, or the NHAS)[6] in July 2010 represented a significant milestone. The NHAS was a White House-level document, complete with the Presidential seal. It was designed as the first cross-government response to HIV, explicitly requiring leadership and action by multiple federal agencies, along with involvement from other stakeholders including the private sector and faith sector, to achieve four major goals:

1. reducing new HIV transmissions;
2. increasing access to care and improving health outcomes for people living with HIV;
3. reducing HIV-related health disparities; and
4. achieving coordination in the national HIV response.[7]

Operational components of NHAS, such as the CDC's Enhanced Comprehensive Prevention Plans (ECHPP) and the "Twelve Cities" approach[8], represented early stages in a geographical approach to test-and-treat type strategies.

In 2015, the NHAS was updated and re-released with new language, new metrics, and a 2020 timeframe for achievements.[9] The four-goal structure remained, with added emphasis on increasing HIV testing and linking people who tested positive to care; providing support to retain PLHIV in care; achieving viral suppression; and focusing HIV efforts on populations most impacted by HIV, including people in the southern states.[10]

The Ending the HIV Epidemic Plan: 2019-present

In January 2019, the U.S. Department of Health and Human Services (HHS) released a ten-year operational plan setting targets of reducing the number of new HIV acquisitions in the United States by 75 percent by 2025, then by at least 90 percent by 2030, through a geographic focus on the 48 hardest-hit counties and the seven states with a "substantial number of HIV diagnoses in rural areas."[11]

This plan is known as the Ending the HIV Epidemic Plan (EHE) and rests on four pillars:

1. diagnose;
2. treat;
3. prevent (through "proven interventions, including pre-exposure prophylaxis and syringe services programs;" and
4. respond to "potential HIV outbreaks to get needed prevention and treatment services to those who need them." [12]

The fourth and final pillar relies on invasive, nonconsensual HIV surveillance activities known broadly as molecular HIV surveillance (MHS) or cluster tracing.[13] Funding has been appropriated from Congress in fiscal years 2020 and 2021 to support the launch of the EHE.[14]

The EHE in its current iteration is viewed by PLHIV networks as deeply flawed in its equation of PLHIV and our viruses to problems that must be surveilled without our consent and managed and controlled via treatment, rather than attending to us as equal citizens with claims to human rights and dignity. We also believe the EHE is necessarily limited in its effectiveness due to its overly biomedical focus, lack of attention to structural and social issues, and failure to partner with PLHIV networks on developing a robust plan and corresponding budget for meaningful community engagement at the federal and jurisdictional level.

The HIV National Strategic Plan: 2021-present

In early December 2020, as the second NHAS was coming to a close, HHS released a draft of a third iteration of a national HIV strategy for public comment, renaming it the HIV National Strategic Plan for 2021-2025 (HIV Plan). A major intent of the draft updated plan was to align the HIV national strategy with the EHE federal initiative. After a brief comment period, the outgoing Trump administration released the 2021-2025 update in mid-January 2021.[15]

PLHIV networks submitted comments on the draft plan, including the HIV Caucus and PWN. The HIV Caucus's and PWN's comments highlighted shortcomings and gaps in the draft plan, notably:

1. the importance of involving organized PLHIV networks;
2. serious concerns with the draft plan's inclusion of the use of HIV genomic sequencing data, cluster detection, and data derived from MHS;
3. lack of inclusion of immigrants and sex workers in the draft plan;
4. inadequate attention to structural determinants of health, most notably racism and racial inequities; and
5. inadequate attention to improving the quality of life of people living with HIV.[16]

We are disappointed to note that PLHIV networks' recommendations were largely not addressed in the final version of the HIV Plan released in January 2021.

The below set of policy recommendations seeks to offer a path forward that will strengthen the overall domestic federal response through a specific focus on improving the structures themselves via which the HIV response is organized and led, along with concrete improvements to major policies guiding that response in the U.S. as of July 2021– the HIV Plan and the EHE. Again, because the HIV epidemic and response are situated within and rest on broader systems, this document also identifies some policy areas of broader focus that must be considered as foundational to creating a safe, dignified, and rights-based environment for people living with and most vulnerable to acquiring HIV.

ISSUE AREAS AND RECOMMENDATIONS

Issue Area 1. Concretely Elevate Meaningful Involvement of People Living with HIV and Disproportionately Impacted Communities in the HIV Response

Meaningful Involvement of People Living with HIV: Defining the Issue

CDC's Notice of Funding Opportunity PS20-2010 acknowledges that "[r]eaching and maintaining viral suppression among people with HIV is the most effective way to reduce new infections."[17] Biomedical tools needed to meet this already exist, such as antiretrovirals, pre-exposure prophylaxis, and post-exposure prophylaxis. The primary impediments to "ending the HIV epidemic" are structural and social; thus, visible, organized, and effective leadership by PLHIV in all aspects of the HIV response is more important than ever.

PLHIV are, by necessity, intimately familiar with factors that place individuals and communities at risk for acquiring HIV in the first place, such as barriers to accessing care and treatment and challenges to living a full and healthy life with dignity. When PLHIV are effectively involved in program and policy development, implementation, and monitoring, the relevance and effectiveness of strategies improve. Moreover, raising visibility of PLHIV and elevating their voices and experiences can help decrease HIV-related stigma and discrimination.

Meaningful involvement of people with HIV/AIDS (MIPA) is a globally recognized principle first articulated in the Denver Principles in 1983 and endorsed by the United Nations Programme on HIV/AIDS (UNAIDS), the body that coordinates global action on the HIV/ AIDS epidemic.[18] As UNAIDS explains, at its most basic level, MIPA does two important things:

1. Recognizes the important contribution that people living with and affected by HIV/AIDS can have in the response to the epidemic as equal partners; and
2. Creates a space within society for involvement and active participation of PLHIV in all aspects of that response.[19]

The HIV Caucus has put forth a body of work that further articulates MIPA within a modern U.S. context to acknowledge that MIPA must fully integrate a lens around racial, gender, class, and other axes of power and privilege to be truly "meaningful." The HIV Caucus definition of MIPA goes beyond merely accounting for HIV-positive status to include representation and expertise from constituencies that are disproportionately affected by the epidemic. Within the U.S. and territories, this means that true MIPA must account for regional differences as well as intentionally developing and supporting leaders living with HIV from marginalized communities, especially Black and Latinx people, youth, people who use drugs, immigrants, the LGBTQ community, cisgender and transgender women, people with incarceration experience, sex workers, people aging with HIV, and so many others.

There is no "one-size-fits-all" model to assure meaningful engagement of community, and it takes time for government and public health partners to build trust with communities that have been harmed by multiple systems. Through real and ongoing partnership with organized, constituency-led formations that reflect most impacted communities, like PLHIV networks, these nuances can be addressed over time.

Involving PLHIV networks in decision-making and implementation translates into concrete benefits for public health leadership, including: pre-existing community trust and cultural humility that facilitates development and implementation of strong programs; a real-time sense of challenges and opportunities on the ground;

informed analysis of the myriad and complex effects of interlocking stigma and discrimination; increased effectiveness of policies and programs; and improved sustainability of projects and organizations.

This space within society can be formalized through various mechanisms. For example, in the Ryan White Part A program, jurisdictional planning councils composed of individuals who make decisions about the allocation of resources are legislatively mandated to meet requirements including "reflectiveness" of the local epidemic and "representation" in filling various types of membership categories.[20] The legislation also mandates that 33 percent of planning council members are people who receive Ryan White Part A services and who do not have a conflict of interest as staff, paid consultants, or board members of Part A funded entities.[21] In addition, guidance followed by the Global Fund reflects clear commitments to this type of structured civil society participation by requiring its Country Coordinating Mechanisms to "show evidence of membership of people that are both living with and representing people living with HIV" and of people from and representing "key populations."[22]

MIPA: Opportunities to Strengthen Meaningful Involvement of People Living with HIV in the Federal Domestic HIV Response

The federal domestic HIV response can be strengthened through true partnership with PLHIV networks. The collective voices and organized leadership of PLHIV, as represented in national and local PLHIV networks, must be viewed as essential to crafting or changing HIV policy; prevention, care, and treatment guidelines; data collection and surveillance practices; the HIV research agenda; in the design of HIV service delivery; and in all aspects of monitoring and evaluation. The best way to achieve this is by consulting and involving PLHIV networks as critical stakeholders and partners at every level of the policy and program decision-making that so profoundly affect our lives.

True MIPA requires resources, planning and accountability, and these must be included in the plan with commensurate metrics, indicators, strategies, and funding.

Currently, neither the HIV Plan nor the EHE have real mechanisms that incorporate the core tenants of MIPA: organized, ongoing, and meaningful engagement with PLHIV. The HIV Plan does not explicitly require federal agencies, efforts, or initiatives to partner with PLHIV networks and lacks any specific accountability to the community of PLHIV. While PS20-2010, an implementation component of the EHE, acknowledges the importance of community engagement as part of its' "respond" pillar and requires that 25 percent of funds be designated towards "community engagement," the CDC's definition of engagement[23] is limited and poorly defined.

Similarly, the three national advisory bodies providing guidance to federal agencies on HIV policy – the President's Advisory Council on HIV/AIDS (PACHA), the CDC/HRSA Advisory Committee on HIV, Viral Hepatitis and STD Prevention and Treatment (also known as CHACHSPT or CHAC), and the Office of AIDS Research Advisory Council (OARAC) -- currently have no formal guidance mandating organized involvement from PLHIV networks, although some of them require representation of PLHIV.[24]

Established in 1993 during the Clinton administration, the Office of National AIDS Policy (ONAP) is tasked with coordinating an integrated response to the domestic and global HIV epidemic, specifically on matters of prevention, treatment and care. ONAP also oversaw community engagement efforts, utilizing both virtual and in-person mechanisms to hear from, connect with, and be accountable to PLHIV.[25]

Unfortunately, the Trump administration shut down ONAP, leaving a significant gap in coordination and dismantling an avenue for community engagement and feedback on federal HIV policy and initiatives like the HIV Plan and EHE.[26]

The Biden administration recently reconstituted ONAP as part of the Domestic Policy Council and appointed Harold Phillips, a Black, gay man openly living with HIV, as director to lead that office.[27] This is a positive step forward in embodying meaningful involvement of people living with HIV. To support that, it is more important than ever that this newly constituted ONAP be equipped to meet the needs of PLHIV. Doing so requires ONAP to be robustly staffed, resourced, and supported to lead the federal response, and to directly engage PLHIV networks as part of its mandate.

Recommendations for Issue Area 1 - Meaningful Involvement of People Living with HIV

Recommended Agency, Federal Body, or Policy	**Recommended Action(s)**
White House/Office of the President of the United States	1. Require ONAP staffing structure to include diverse PLHIV from the communities most impacted by the epidemic, including Black gay and bisexual men, Black cisgender women, and transgender women of color. 2. Recharter PACHA, CHAC and OARAC to each include at least two standing seats for designated representatives of the HIV Caucus, to be filled by the HIV Caucus utilizing representatives of our own choosing.
Department of Health and Human Services	1. The Office of HIV/AIDS and Infectious Disease Policy should develop a formal and regular process to solicit input from, engage and consult with the HIV Caucus, as the representative collective of all U.S.-based national PLHIV networks. 2. Amend the HIV Plan to include measurable metrics for formal engagement of PLHIV networks. 3. Amend the EHE and future funding related to it to: 4. Redefine community engagement beyond resourcing already developed plans, including paid consultation and decision-making on all aspects of the EHE by PLHIV networks; 5. Apply such a commitment to community engagement across the EHE plans – beyond but including the "cluster detection and response" pillar. 6. Amend the EHE, the HIV Plan, and require future HIV initiatives to require MIPA indicators for federal, state, and local advisory and decision-making bodies with purview over HIV, including local EHE jurisdictional planning processes. The required MIPA indicators should include meaningful PLHIV engagement and leadership from the communities most impacted by the domestic epidemic.

PLHIV have been responsible for mass shifts in the ways that HIV is understood, prevented, treated, and addressed: our activism, choices, and actions have built organizations, fought stigma, and advanced science. We are a powerful and underutilized resource that, when supported and engaged appropriately, can dramatically improve efficacy of public health interventions and programs, reduce HIV transmission, and improve quality of life and health outcomes for PLHIV. The federal response can structurally achieve this by making a formal commitment to measurable MIPA.

Issue Area 2. Proactively Create an Affirming Human Rights Environment for People Living with HIV: Address Stigma; Eliminate HIV Criminalization and Halt Molecular HIV Surveillance

2A. Addressing HIV-Related Stigma.

HIV-Related Stigma: Defining the Issue

HIV-related stigma and other intersectional stigmas persist among and against PLHIV. Intersectional stigma refers to the ways that multiple kinds of stigmas - around gender identity, sexual orientation, socioeconomic class, mental health, history of drug use, incarceration, and/or sex work - are compounded for some PLHIV.[28] These have deleterious impacts on people's lives, as they experience further marginalization from communities and institutions. Intersectional stigma also can result in being targeted by multiple punitive laws and policies, as well as bias and discrimination in health care, law enforcement, employment and education.

Where most of the literature places HIV-related stigma either as a psychodynamic model (how people feel) or related to a public health outcome (clinical usage), PLHIV experience stigma throughout every part of their lives. Legal frameworks such as HIV criminalization provide powerful proof of institutionalized stigma. Stigma affects how PLHIV find support,[29] whether PLHIV are successful in pursuing education and employment,[30] and overall quality of life[31].

The result of these stigmas is often seen in the lack of social protections provided to the diverse communities of PLHIV. Criminalization based on HIV-status is one clear aspect of this, yet PLHIV face multiple vulnerabilities. Punitive laws around sex work and drug use affect PLHIV, as well as how intensive policing disproportionately affects the Black community, people of transgender experience, people with disabilities, and immigrants in the U.S. The EHE notes that HIV-related stigma, homophobia, and transphobia are contributing barriers to a successful HIV response, yet there is no clear initiative in the $670 million plan to address and dismantle these barriers.[32]

In order to address these issues, the Global Network of People with HIV/AIDS (GNP+) developed the People Living with HIV Stigma Index (Stigma Index).[33] The Stigma Index is a community-led way to document stigma in a country and develop action plans to address it. The Stigma Index has been conducted in over 100 countries with over 100,000 people living with HIV involved.[34] In the U.S., the attempt to conduct the Stigma Index was cut short due to funding.[35]

HIV-Related Stigma: Opportunities to Strengthen the Federal Response

The HIV Plan envisions "every person with HIV ha[ving] high-quality care and treatment and liv[ing] free from stigma and discrimination," and HIV-related stigmas in the form of interpersonal, community, health system, and structural stigma and discrimination are acknowledged as a barrier to achieving public health goals throughout it.[36] HIV-related stigma is framed as a problem, a challenge to overcome, and a barrier throughout the HIV Plan, which proposes some concrete and useful strategies to address this: developing and implementing campaigns and resources to reduce HIV-related stigma;[37] training health care staff on stigma and discrimination;[38] increasing health literacy among patients; supporting communities to address HIV-related stigma;[39] reframing public health and HIV messaging campaigns that may perpetuate stigma;[40] and developing and implementing evidence-based interventions designed to reduce HIV-related stigma and discrimination in public health and health care systems[41]. Indeed, HIV-related stigma and discrimination may be the problem and barrier to achieving HIV prevention, care, and treatment goals most consistently identified throughout the HIV Plan.

Despite this overwhelming acknowledgment that HIV-related stigma represents a tremendous barrier, there is only one indicator within the HIV Plan that holds the federal response accountable to address this. It holds measurable success solely at the individual level, suggesting the use of a 10-item questionnaire to assess whether individuals diagnosed with HIV are experiencing reduced stigma.[42] The HIV Plan and broader federal HIV response would benefit from ensuring that its metrics to assess success in reducing or eliminating HIV-related stigma are grounded in what PLHIV are asking for and that they seek to address individual, community, and structural HIV-related stigma and discrimination.

Recommendations for Issue Area 2A - Addressing HIV-Related Stigma

Recommended Agency, Federal Body, or Policy	**Recommended Action(s)**
Department of Health and Human Services	1. In partnership with PLHIV networks, identify specific stigma-reduction activities that health departments, AIDS Service Organizations (ASOs) and Community-Based Organizations (CBOs), health clinics and other partners in the HIV response can engage in. 2. Require grantees to address employment barriers at all levels for PLHIV as an important way to combat stigma. 3. Resource PLHIV networks to develop and implement stigma-reduction initiatives that reflect the intersectional kinds of stigma that impact the local community of PLHIV.
HIV National Strategic Plan	1. Center the lived experience of intersectional stigma amongst PLHIV, inclusive of Black, Indigenous, and other people of color; people of transgender experience; gay and bisexual men; sex workers; people who use drugs; immigrants; and people who are incarcerated and in other institutional settings. 2. Utilize data collection tools and interventions that go beyond individual feelings and examine structural change, such as, the GNP+ Stigma Index 2.0. This could include building and resourcing PLHIV networks.
Ending the HIV Epidemic Plan	1. Require jurisdictions to have clear, actionable, resourced community-led initiatives to reduce HIV-related stigma and other intersectional stigmas. 2. Identify resources that work towards community-led stigma reduction and community resilience building in its portfolio. 3. Promote advocacy efforts to remove punitive laws and policies and acknowledge how they contribute to HIV-related stigma.

2B. Eliminating HIV Criminalization

HIV Criminalization: Defining the Issue

HIV criminalization is the unjust use of criminal laws, policies, and practices to police, regulate, control, and punish PLHIV based on their HIV-positive status. HIV criminalization laws exist at the state level and vary in scope from state to state.[43] HIV-specific laws may criminalize a range of activities including alleged HIV non-disclosure prior to sex, potential or perceived HIV exposure through many different means, or unintentional transmission of the virus.[44] Although these laws do not exist in every state or territory in the U.S., PLHIV have been convicted or received sentence enhancements based upon their HIV status even when no HIV-specific statute exists,[45] and even when no risk of HIV transmission was scientifically possible.[46]

By contributing to an environment where PLHIV can be targeted and punished, HIV criminalization laws present a deterrent to achieving federal HIV prevention and care goals, while institutionalizing HIV stigma as part of the legal system. Furthermore, data from several states with HIV criminalization laws provide evidence of racial and gender bias in their application, disproportionately enforced against Black and Latinx gay and bisexual men and cisgender and transgender women.[47]

HIV criminalization inflicts long-lasting harm on PLHIV, their families, and their communities. A prosecution or investigation related to HIV status itself and negative media attention may lead to violations of confidentiality, job loss, housing insecurity, complications with custody arrangements, and more. A conviction under an HIV criminalization law may lead to a person being placed on a sex offender registry, which has implications for stigma, childcare, housing, employment, food security, and mental and emotional well-being.[48] Thus, the practice of criminalization is in direct opposition to strategies that seek to improve access to and sustained connection to prevention and treatment methods for the most vulnerable populations.[49]

HIV Criminalization: Opportunities to Strengthen Federal Leadership

Both the HIV Plan and EHE advise state governments to reform or repeal HIV criminalization laws and practices,[50] but do not provide resources or requirements in their respective plans.

EHE does not require its priority jurisdictions to address criminalization in their plans,[51] leaving it up to each jurisdiction to decide for themselves whether to address their respective HIV criminalization laws.[52]

The HIV Plan recognizes the detrimental impact HIV criminalization has on PLHIV, noting how it fuels HIV-related stigma and discrimination.[53] To achieve the goal of ending HIV-related stigma and discrimination, the HIV Plan provides one strategy that calls for reforming state HIV criminalization laws to be rooted in science and public health strategies.[54] It also identifies the need to educate legislators, prosecutors and law enforcement on HIV transmission risks.[55]

Federal leadership on the HIV response has an important role to play in creating an affirming legal, social, and political climate for people living with and vulnerable to HIV to engage in health care and have all their human rights protected.

Recommendations for Issue Area 2B - Eliminating HIV Criminalization

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
HIV National Strategic Plan	1. Draw clear connections between criminalization and the disparate health outcomes of various groups such as Black, Indigenous, and other people of color, sex workers, and those who use drugs. 2. Strengthen the focus on negative consequences of criminalization on access to and retention in HIV care and treatment.
Ending the HIV Epidemic Plan	1. Acknowledge the federal government's role in creating HIV criminalization laws and make equal commitments to repeal these laws. 2. Require EHE jurisdiction plans to include clear commitments to support state efforts to reform or repeal HIV criminalization laws as a condition for funding. 3. Call for EHE jurisdictions that are being funded to engage with PLHIV who have experienced incarceration to address the residual impacts of criminalization, including access to adequate treatment and care.
Congress	1. Pass a Repeal Existing Policies that Encourages and Allow Legal (REPEAL) HIV Criminalization Act that is consistent with current HIV decriminalization advocates' understanding and strategy and that incentivizes states to reform or repeal their respective laws.

2C. Declare a Moratorium on Molecular HIV Surveillance Until Adequate Safeguards Protecting the Privacy and Autonomy of People Living with HIV Are Implemented

Molecular HIV Surveillance: Defining the Issue

Molecular HIV surveillance (MHS) refers to the practice of using HIV genetic material to compare with other HIV genomic sequences to determine whether acquisitions are similar enough to be related to each other and therefore linked. For PLHIV, MHS begins in the clinical setting by which during a medical visit, often early in an individual's diagnosis, blood is drawn and from it HIV genetic material is sequenced, stored in a database, and shared with other databases. For public health purposes, MHS is primarily used for "cluster detection," or the practice of identifying instances when it appears there may be multiple linked HIV acquisitions appearing within a short amount of time, thereby triggering a public health investigation and response. Of notable concern, the processes of HIV genomic sequencing, data storage, and data sharing -- essential to MHS -- are conducted without an individual's consent and knowledge.

As PLHIV networks, we strongly oppose these practices for several reasons that generally fall into the following categories, some of which are interlinked:

1. Lack of informed consent from PLHIV;
2. Lack of consultation or meaningful engagement with PLHIV in development and implementation of MHS;
3. Wide variation in state-level data sharing environments and legal protections for MHS data;
4. Risk of potential data misuse in civil, immigration, and/or criminal proceedings;
5. Concerns about breaches of privacy and confidentiality; and
6. Lack of consistent standards for competency in the HIV disease investigation intervention workforce to attend to sensitivities around stigma, culture, and violence.

Lack of consent from and consultation with people living with HIV.

PLHIV generally do not know, nor have consented, to having our HIV genomic sequence data collected, shared, stored, and utilized in this way by public health authorities. This is a fundamental breach of trust. Due to the lack of informed consent, MHS may undermine trust in the health system, deterring people from seeking HIV screening and testing in the first place and from engaging in health care once diagnosed. This presents a serious problem for "ending the HIV epidemic" efforts. PLHIV tend to be from communities that already have justifiable distrust of medical and research institutions, as well as public health authorities, and may have made significant efforts to overcome that distrust to participate in their health care.[56]

HIV clinicians and health care providers frequently go to great lengths to ensure safety and confidentiality for their patients – and cannot opt out of the use of this medical information for surveillance purposes.[57]

While PS20-2010, which is an implementation component of the EHE, acknowledges the importance of community engagement as part of its "respond" pillar and requires that 25 percent of funds be designated toward "community engagement,"[58] this is too little, too late, considering that several years ago, the CDC's PS18-1802 mandated funded health departments to tackle MHS as a core component of their prevention efforts[59].

Wide variation in state-level data sharing environments and legal protections for MHS data.

Laws protecting the privacy of health data and permitting sharing and use of molecular HIV data vary widely from state to state, and there is no current national standard that would uniformly protect misuse of this data for people living with HIV.[60] The National Association of State and Territorial AIDS Directors (NASTAD) produced an analysis of the legal and regulatory HIV data privacy environment in ten states and found wide variation in how well HIV data is protected and under what conditions personally identifiable data may be shared without the person's consent, including sharing HIV data with law enforcement.[61] In particular, NASTAD's report found that:

> "In general, statutes provided health departments with authority to disclose personally identifiable HIV data without consent (emphasis added) for the following general purposes: surveillance, investigation, or control of communicable disease; treatment, payment, research, or health care operations; justifiable public health need. Within this broad statutory authority, a few states enumerated specific allowable and unallowable health department HIV data-sharing activities (particularly for data-sharing related to law enforcement and research). However, the vast majority of statutory schemes used more general language giving discretion to health departments and their legal counsel to act under fairly broad authority as long as the statute's purposes were met. This lack of specificity in state laws places great importance on health department internal data-sharing policies and gatekeeping functions."[62]

While every state had protections for reducing data shared with law enforcement, states vary on the strength of the legal protections in place to compel a health department to produce HIV data, and which data may be shared, for law enforcement purposes. Ultimately, much is left up to the discretion of the health department's legal counsel. Further, there is substantial variation in legal authority to share personally identifiable information of PLHIV for research purposes.[63]

Risk of potential data misuse in civil, immigration, and/or criminal proceedings.

As acknowledged in the HIV Plan, over 30 states still have laws criminalizing PLHIV, and even more prosecute PLHIV under other general criminal laws, including assault.[64] Among PLHIV, Black and Latinx people, sex workers, queer and trans people,[65] immigrants, those who are unhoused or marginally housed,[66] people who use drugs, and people who live with mental illness are already frequently targeted by law enforcement.[67] In criminal prosecutions for alleged HIV exposure, prosecutors may seek to introduce evidence that the defendant or plaintiff is part of a transmission cluster.[68] Judges, prosecutors and juries may be biased due to stigma and may also not understand the science enough to know its limitations (for example, MHS cannot currently demonstrate direct transmission, only whether viruses are closely related). For immigrants of any legal status, it is unclear what protections exist if MHS data were presented in immigration proceedings. This creates further vulnerability for communities already vulnerable to surveillance and policing.

Concerns about breaches of privacy and confidentiality.

Attention from public health departments and from media linked to "cluster detection" investigations can disclose private health information of PLHIV, even inadvertently. One newspaper in Seattle went so far as to publicly identify a street on which an "HIV outbreak" was happening and to name that the people involved were unhoused, sex workers, and/or drug users.[69] This type of disclosure presents a risk of further targeting from police for PLHIV. Worse, it is well documented that PLHIV have lost jobs,[70] housing, and even their lives[71] as a consequence of disclosure of HIV status. These types of irresponsible actions by public health officials can literally put our lives at risk.

Health department workforces do not have consistent standards for training and implementation that protect people living with HIV from possible harm.

While the CDC recognizes the need for the public health workforce to receive training in culture and diversity,[72] it is unclear to what extent contact tracers, disease investigators, or cluster detection responders are receiving specific training in the nuances of HIV stigma, disclosure and privacy sensitivities, and risks for community violence and criminalization. Cultural competence is a necessary skill for members of the public health workforce engaged in such sensitive activities, and recommendations from experts support ensuring that under-represented populations, such as PLHIV, are involved in developing effective health solutions.[73]

Dr. George Ayala and other PLHIV have called for not offering partner notification services where PLHIV and other socially marginalized groups are criminalized[74] if the risks of doing so outweigh the benefits.[75] Anecdotally, there are many examples of public health HIV contact tracing activities paving the way for inadvertent disclosure of HIV-positive status in employment settings, housing, and with family members. Significant and ongoing workforce training is necessary to ensure safety for people living with and vulnerable to HIV who may be involved in cluster detection investigations.

In summary, the practice of MHS, cluster detection, and corresponding public health investigations create vulnerabilities for inadvertent disclosure; stigma; risks to physical safety, employment, and housing; and even criminal liability for PLHIV. MHS and cluster detection practices must be stopped immediately and have no place in any national HIV plan until significant steps are taken to address these concerns. Sharing of HIV data is a sensitive issue and must be thoughtfully considered in real, meaningful partnership with PLHIV networks before it is further implemented.

Opportunities to strengthen HIV data privacy and sharing protections

Currently, MHS comprises one of four pillars of the EHE.[76] Recent federal budgets have prioritized CDC funding for cluster detection and response[77], and the CDC is essentially requiring health departments funded under EHE efforts systematically implement and/or scale MHS activities.[78] The HIV Plan also highlights MHS and cluster detection and response among "activities that exemplify improved integration and coordination of efforts" -- which is one of the four primary goals of the HIV Plan.[79] Further, the HIV Plan explicitly names the need to improve coordination "across partners to quickly detect and respond to HIV outbreaks" as a strategy.[80]

The HIV Plan explicitly calls for "enhanc[ing] the quality, accessibility, sharing, and use of data, including HIV prevention and care continuum data and social determinants of health data," and goes on to describe data sharing across disparate systems as a top priority.[81] Such an expansion of

MHS without strong and consistent data privacy and confidentiality laws, coupled with boundaries on the sharing of HIV genomic sequence data and identifiable information about PLHIV, is dangerous and irresponsible.

Health departments describe the CDC's 2011 guidance on HIV data privacy and security as a crucial resource in informing their own internal data privacy policies.[82] That guidance explicitly states that "data collection and use policies should reflect respect for the rights of individuals and community groups and minimize undue burden."[83] It calls for training of individuals who have access to identifiable health information in policies and procedures for data sharing, laws governing data sharing, procedures for storing data – but does not require any training in, for example, specific sensitivities around HIV stigma, criminalization, and other dangers of HIV-positive status disclosure.[84]

PLHIV networks are not alone in their call for adequate legal safeguards and community education on MHS. AIDS United's Public Policy Committee has issued a strong set of principles and recommendations to guide the use of MHS.[85] We support many of these recommendations and have provided additional recommendations below:

Recommendations for Issue Area 2C - Molecular HIV Surveillance

Agency, Federal Body, or Policy	**Recommended Action(s)**
Department of Health and Human Services	1. Work in collaboration with PLHIV networks to develop and implement a process to obtain informed consent from PLHIV before HIV genomic sequence data is collected, analyzed, stored, and/or shared. 2. Issue a public statement that affirmatively clarifies that HIV genomic sequence data cannot be used in criminal, civil, or immigration proceedings. 3. Work in collaboration with the HIV Caucus to develop consistent national standards on HIV data security, sharing, and storage that explicitly prohibit sharing HIV genomic sequence data with law enforcement, immigration enforcement, employers, and other relevant entities and which limit the amount of time HIV data can be stored and how it may be shared.
Ending the HIV Epidemic Plan	1. Remove the requirement that EHE-funded jurisdictions conduct MHS activities. 2. Prohibit EHE-funded jurisdictions from conducting MHS activities if they cannot meet the security, storage, and data-sharing standards described above.
HIV National Strategic Plan	1. Remove MHS and all cluster detection and response activities from the HIV Plan until the above issues have been addressed.
White House Office of National AIDS Policy	1. Declare an immediate moratorium on the further collection, use, and sharing of MHS data in public health efforts until the above standards are achieved. 2. Develop community engagement standards that require active involvement from PLHIV networks in any future development of HIV-related data collection, use, sharing, and storage.

Centers for Disease Control and Prevention	1. Require that any jurisdictions funded to conduct MHS prove they can meet the standards created above. 2. Require certification from state and local jurisdictions that public health officials will comply with CDC data security guidance and only share data with law enforcement pursuant to a valid, enforceable court order issued following notice to the subject(s). Effective notice should both inform subjects that their data has been sought and provide them an opportunity to oppose disclosure in court. 3. Fund initiatives to educate public health department staff and legal counsel on the legal safeguards and required processes and protections for disclosing public health information to law enforcement. 4. Make funding for MHS and research based on MHS contingent upon such certification. 5. Partner with the HIV Caucus to develop and implement a curriculum for relevant public health workforce staff inclusive of content on HIV stigma, HIV criminalization, cultural sensitivities on HIV, and risks of HIV status disclosure. 6. Require that all staff involved in disease investigation, contact tracing, partner notification, MHS, and cluster detection response receive this training. 7. Require that HIV genomic sequence data be stored in an anonymized form that cannot be re-identified. This should include the use of advanced anonymization techniques that make molecular surveillance data resistant to re-identification by algorithms or humans. 8. Develop standardized, publicly available disclosures to ensure that PLHIV are informed of routine and potential use of their identifiable health information, including any contemplated use of individual, identifiable treatment information and resistance testing results, and including their right to object to having their data used in this this way.

Issue Area 3: Addressing Inequities in the Federal Response: Attend to Racial and Gender Disparities

Addressing Racial and Gender Inequities in the Federal Response: Defining the Issue

Racial Inequities. HIV has a disproportionate impact on Black, Latinx, and Indigenous communities which is inadequately addressed by every domestic HIV plan. The CDC has consistently found that Black and Latinx communities are disproportionately affected by HIV compared to other racial/ethnic groups. For example, while Black individuals represented 13 percent of the U.S. population, they represented 41 percent of PLHIV in 2018 CDC data.[86] While Latinx individuals represented 18 percent of the population, 23 percent of PLHIV were Latinx in the same year.[87] In the U.S., gay and bisexual men - particularly Black, Latinx and Indigenous - constitute the majority of new HIV diagnoses, yet this is not reflected in funding and resources for community-led programs.[88]

Among cisgender and transgender women, Black women are disproportionately affected by HIV as compared to women of other races/ethnicities.[89] From 2014-2018, the rate of new HIV acquisitions among cisgender Black women was 13 times that of white women and four times that of Latinx women.[90] Further, in 2017, Black Americans had an age-adjusted HIV-related death rate of 6.6 per 100,000, compared to 0.9 per 100,000 for white Americans.[91]

The impacts of structural racism[92] are not limited to relative rates of HIV acquisition. They impact all areas of life, including economic opportunity and justice, well-being, and mental health care. Until structural racism and racism within the HIV epidemic is explicitly recognized and addressed, the HIV epidemic will not end. Expanding biomedical responses without attention to the racism that prevents Black, Latinx, and Indigenous people from accessing HIV prevention, care, and treatment in the first place will only further the racial disparities in the HIV epidemic. Instead, the focus must be on structural and social drivers of health; dismantling oppressive, discriminatory systems; and understanding and ameliorating the effects of understandable medical mistrust.

Gender Inequities. Women, including women of trans experience, account for about a quarter of the domestic HIV epidemic.[93] In 2018 alone, an estimated 7,189 cisgender women and 554 transgender women were newly diagnosed with HIV in the United States.[94] The single largest percentage increase in the number of persons living with HIV from 2014 through 2018 by gender was among transgender women.[95] Gender disparities are also racialized and geographic: Black, Latinx, and other women of color represent a majority of women living with HIV in the United States and a majority of new HIV acquisitions.[96]

Black cisgender women, who live at the intersection of anti-Black racism and gender-based oppression, are disproportionately impacted by HIV.[97] Cisgender women with HIV are concentrated in the South, which in 2018 had more reported HIV acquisitions (3,988) among adult women and adolescents than any other region.[98]

In health care settings, stigma and bias against transgender people may compromise access to quality services, as well as policies restricting what can be covered by payer sources. Transgender people face discrimination in all aspects of life, from housing to health care, from public accommodations to policing, from employment to education. Again, race and gender intersect in complex ways: Black, Indigenous, and other transgender people of color face even higher rates of discrimination and violence in these settings. In health care settings, stigma and bias against transgender people itself may compromise access to quality services, as well as policies in the form of structural stigma that restrict what can be covered by payer sources. While important moves have been made to restore non-discrimination protections, for transgender people living with HIV, it can still be nearly impossible to find culturally relevant and non-stigmatizing health services and providers.

Transgender and cisgender women living with and at risk for HIV face severe challenges to accessing services, health care, and information they need, including socioeconomic and structural barriers such as poverty, cultural inequities, and intimate partner violence (IPV).[99] Women living with HIV are more likely to receive some care, but less likely to be retained in care, as compared to the statistical average person living with HIV.[100]

The rates of death among PLHIV reflect this disparity, as cisgender women, transgender women, Black people, people of more than one race, and people in the South saw smaller gains in their rates of deaths from HIV from 2010 until 2018 than other PLHIV, and women are more likely to die of HIV related complications than men.[101] Higher percentages of cisgender women and transgender women who are clients of the Ryan White HIV/AIDS Program are living below the federal poverty line than men.[102] Fifty-five percent of women living with HIV report experiences of intimate partner violence, and the associated trauma can also lead to poor treatment outcomes and higher transmission risks.[103] Without focused attention to racial and gender inequities, these interrelated disparities will continue to persist.

Racial and Gender Disparities: Opportunities to Strengthen Federal Leadership

As noted above, both the EHE and the HIV Plan do not provide enough focus and concrete steps to address gender or racial disparities as they pertain to PLHIV. The racial inequalities of the federal response can be more firmly grasped by reviewing the way funding is provided to grantees as part of the EHE plan.[104] The first three Notice of Funding Opportunities[105] make no mention of racial disparities as it pertains to HIV, except to give an example of a program focused upon Black men who have sex with men.[106] However, addressing the needs of Black, Latinx, and Indigenous people who are disproportionately affected by the epidemic is not mentioned in any of these three funding opportunities.[107] Even when Black, Latinx, Indigenous, and people of color do begin to be noted as under-served populations, there is no focus outside of viral suppression[108] or access to PrEP.[109] HIV-related stigma as it intersects with racial disparities is only mentioned in one funding opportunity, and there it is not substantively addressed.[110]

As with racial disparities, cisgender women[111] and transgender people are generally not prioritized in funding decisions. When women are mentioned, it is generally in the context of PrEP access or testing,[112] not sexual and reproductive health care needs, care-taking responsibilities, or the other unique needs of women. Even when women are addressed in funding opportunities, these opportunities are grossly underfunded when compared to the scale of the issues.[113]

While racial disparities have been more fully addressed in the HIV Plan, which includes concrete commitments to strengthen civil rights laws,[114] its discussion of other social and structural drivers of health which result in racial disparities is lacking.[115] While these issues[116] are addressed more broadly as they relate to all under-served populations, there are no commitments to address these issues directly as to how they impact Black, Latinx, and Indigenous communities.[117]

Similarly, gender disparities also receive a more complete, yet still inadequate treatment in the HIV Plan. We are pleased to see that transgender and Black women are noted as priority populations.[118] Further, the need to scale up trauma-informed services is included as a goal.[119] The need for comprehensive, supportive services for transgender individuals as well as a discussion of the challenges that exist is present; however, the indicators of success are biomedical indicators of viral suppression.[120] Still, the HIV Plan makes no mention of sexual and reproductive health,[121] of gender specific disparities in employment and housing, and other challenges to care and well-being that exist, such as care-taking responsibilities, discrimination based upon gender, and mistrust of medical professionals.

Recommendations for Issue Area 3 - Inequities in the Federal Response

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
White House/Office of National AIDS Policy	1. Explicitly center racial equity throughout the federal HIV response by including Black, Latinx, Indigenous, and other people of color as priority populations in funding opportunities. 2. Explicitly include racial and gender disparities as elements to be addressed in all grant funded opportunities.
Department of Health and Human Services	1. Fund via grants Black-led organizations addressing the epidemic through a racial equity lens. 2. Fund programs led by women and people of trans experience to address the HIV epidemic through a gender equity lens.
End the HIV Epidemic Plan	1. Require that jurisdictional resources be targeted for Black, Indigenous, and other people of color, especially those who are also gay and bisexual men, people of trans experience, people who use drugs, sex workers, and immigrants. 2. Create funding opportunities that specifically address social and structural drivers of health as they relate to Black, Indigenous, and other people of color. 3. Prioritize funding for organizations run by members of the communities to be served. 4. Require grantees to include intimate partner violence screenings in health care and supportive service settings. 5. Require jurisdictions to create and fund programs that provide care-taking services for the dependents of PLHIV while they are receiving services.
HIV National Strategic Plan	1. Include a racial and gender equity lens that is informed by the direct inclusion of community by hiring them as staff in federal agencies and paying them for their work. 2. Utilize multiple factors to gauge the success of the HIV Plan outside of viral suppression.

Issue Area 4. Add Sex Workers and Immigrants Living with HIV as Priority Populations Throughout the Federal Response.

Sex Workers Living with HIV: Defining the Issue

Sex workers are at a greater vulnerability for acquiring HIV and other STIs than the general population.[122] For transgender women, those who had ever done sex work were over 25 times more likely to be living with HIV (15.32 percent) than the general population (0.6 percent).[123] This is due to various social and structural factors that create substantial barriers to HIV prevention, treatment, and care, such as criminalization of sex work, lack of employment protections for sex workers, and intersections between poverty and sex work, which may increase vulnerability in the first place.

Criminalization of sex work takes many different forms, including targeted and often racist,[124] homophobic, and/or transphobic policing of people perceived to be engaged in sex work under various forms of loitering laws, "condoms as evidence" laws--which create a structural barrier to sex workers protecting their own sex health-- and intersections with HIV criminalization laws.[125]

Sex workers are also at increased risk for violence from community and from law enforcement,[126] and, in many U.S. states and territories, bear the brunt of HIV-related prosecutions, convictions, and sentence enhancements.[127] Practices such as "cluster detection and response," under the umbrella of MHS activities embedded in the EHE's implementation, have even led to media disclosures that specifically name streets where sex workers and people who use substances live and/or work.[128] HIV services and government programs may themselves stigmatize and structurally exclude people in the sex trade.[129]

To truly end the HIV epidemic, the HIV Plan must assure that competent and non-stigmatizing HIV services are provided to sex workers and that sex workers can safely participate in HIV services and benefit from other publicly funded programs without fear of judgment, criminalization, exclusion, or confidentiality violations. To ensure this is possible, sex work must be fully decriminalized; HIV-related sentence enhancements for sex work must be repealed; and sex workers, especially from Black, Indigenous and people of color communities, should be meaningfully engaged as partners in designing and implementing HIV prevention, care, and anti-stigma efforts.

Immigrants Living with HIV: Defining the Issue

Immigrants have been excluded from most health services due to legislative and regulatory exclusions.[130] Even with the advent of the ACA, millions of undocumented individuals remain unable to access health care and other services that support access to health care.[131] In addition, fear for safety and language injustice persist as barriers, particularly in the last five years.

Regulatory barriers have been erected to prevent immigrants living with HIV from accessing systems of care they need and have a right to, including health care.[132] These barriers have fueled medical mistrust and service avoidance among immigrant communities, specifically Black, Latinx, and Asian communities – communities that intersect with the HIV Plan's named priority populations.[133] For example, in 2019, the Trump administration promulgated a rule radically redefining the "public charge" test, essentially punishing some immigrants for relying on public programs like health care, housing and nutrition programs.[134] While the Trump administration's rule has been blocked, the chilling effect[135] will be long-lasting and will exacerbate health disparities.

In addition to traditional medical service providers, the U.S. Immigration and Customs Enforcement (ICE) has been utilized and is tasked with providing care to immigrants in detention centers.[136] Carceral systems, including ICE detention centers, have consistently failed to provide quality and competent health care to immigrants living with HIV. ICE's gross medical negligence has led to the death of some.[137] Roxsana Hernández and Johana Medina, both transgender women, sought asylum in the U.S. based on their HIV status, but were denied medical care and died in ICE custody. Despite the legal requirement to provide immigrants in detention with medical treatment and care, ICE refused to provide HIV treatment for Hernandez, resulting in her death.[138] The HIV Plan cannot ignore the detrimental impact detention and incarceration has on migrants living with HIV -- this must be included in any plan to address the HIV epidemic, regardless of someone's immigration status.

For non-English speaking immigrants, language barriers may play a role in exacerbating health disparities for marginalized communities.[139] The HIV Plan briefly mentions language barriers but fails to convey the ways that culture is embedded in language, and thus that translation and interpretation go beyond a straightforward word-for-word translation. Language justice is about access, in terms of its accessibility and engagement with communities. It is about making health terms and information understood and communicated within cultural context, with cultural relevance, so that community members can make thoughtful health choices and assert their decisions. To achieve the prevention and care goals of the HIV Plan, immigrants of any legal status and immigrants who do not speak, read, or write English must be assured high-quality HIV prevention, care and facilitative services; must be able to participate safely and without financial or legal repercussions in HIV programs; and must have unfettered access to treatment.

Opportunities to Strengthen the Federal Domestic HIV Response for Sex Workers and Immigrants

The HIV Plan currently recognizes five populations as "priority populations":

1. gay, bisexual, and other men who have sex with men, in particular Black, Latino, and American Indian/Alaska Native men;
2. Black women;
3. transgender women;
4. youth aged 13-24; and
5. people who inject drugs.[140]

Notably absent from the HIV Plan are sex workers and immigrants, two communities that have specific needs in relation to HIV and which are often structurally absent from decision-making and advisory processes, for a range of reasons. While the final version of the HIV Plan does minimally mention sex work and immigration status in the context of stigma and discrimination,[141] it fails to articulate a commitment to address these needs systematically throughout the federal response, for example within HIV prevention and care efforts; nor does the HIV Plan articulate concrete strategies that could better meet the goal of reducing HIV-related stigma and discrimination for these populations, improve their engagement in health care, and eliminate barriers to HIV prevention efforts.

Recommendations for Issue Area 4 - Sex Workers and Immigrants as Priority Populations

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
White House/Office of the President	1. Advocate for legislation to prohibit the practice of using condom possession as evidence of sex work 2. Modify or eliminate existing federal policies that conflate sex work and human trafficking and that prevent sex workers from accessing services such as health care, HIV prevention, and support. 3. Work with the Office of the Global AIDS Coordinator to repeal "anti-prostitution pledge" requirements entirely from PEPFAR and anti-trafficking funds. 4. Ensure health care access regardless of an individual's immigration status. 5. Prioritize funding to community-based organizations led by and/or serving immigrant populations.
Department of Health and Human Services	1. Implementation plans for the HIV Plan should address training of health care professionals to end stigma and discrimination against those who are involved in the sex trade. 2. Prioritize funding for harm reduction and rights-based health care services for sex workers of all genders and all ages. 3. Require meaningful engagement of Black, Latinx, Indigenous, and other people of color communities-- especially PLHIV, people who use drugs, immigrants, sex workers, people of trans experience, and gay and bisexual men--in HIV planning and resourcing in every health jurisdiction. 4. Fund CBOs to strategize, inform, and implement programs and policies in the HIV response. 5. Develop and implement community-accountability models for public health jurisdictions to ensure that those most marginalized are indeed reached.
Centers for Disease Control and Prevention	1. Issue a statement that explains how laws that rest on condom possession as evidence of sex work harm HIV prevention, testing, and clinical care efforts and may place sex workers at risk for violence.
Congress	1. Pass the SAFE Sex Worker Study Act of 2021 2. Pass the HEAL for Immigrant Families Act of 2021 3. Pass the American Dream and Promise Act of 2021 4. Repeal exclusions and eliminate policies that prevent and/or hinder individuals with commercial sex and drug-related convictions from applying for and/or receiving student loans, public housing or housing assistance, public assistance, or other government-funded social services.

HIV National Strategic Plan	1. Add sex workers as a priority population. 2. Add immigrants, of any legal status, as a priority population. 3. Explicitly recommend resourcing for community-led organizations and programs for people of color, especially in the following communities: people living with HIV, people who use drugs, immigrants, sex workers, people of trans experience, and gay and bisexual men. 4. Discourage "general public" approaches in the HIV response. This "general public" affirms a white, cisgender, able-bodied, middle class norm that excludes everyone else. 5. Explicitly name and call for addressing the criminalization of sex work and stigma and discrimination against sex workers as a barrier to HIV prevention, care, and anti-stigma efforts. 6. Prioritize funding and partnership opportunities with community-based organizations led by and for sex workers. 7. Prioritize funding for in-person interpreters and other translation services for people with limited English proficiency. 8. Prioritize funding immigrant-led and immigrant- serving community-based HIV organizations for communication and health literacy programs. 9. Require AIDS service organizations (ASOs) to staff certified medical interpreters and/or train staff on proper interpreter utilization. 10. Ensure that translation includes understanding cultural contexts and frameworks for health, disease, and treatment options.
End the HIV Epidemic Plan	1. Require EHE-funded jurisdictions to demonstrate a commitment to decriminalizing commercial sex work, including addressing loitering laws and condoms as evidence laws. 2. Require EHE-funded jurisdictions to include resources for community mobilization of sex workers to respond to violence and discrimination.

Issue Area 5. Affirmatively Commit to Improving Quality of Life for People Living with HIV.

Improving Quality of Life for People Living with HIV: Defining the Issue

Although there are more than a million PLHIV in the United States, quality of life for PLHIV has long been an afterthought in the federal HIV response. While the HIV Plan makes "improv[ing] the health-related quality of life" for people aging with HIV a "key commitment"[142] and also seeks to both develop and scale interventions to improve quality of life for people living with HIV,[143] it does not do so in a broad and inclusive way. Both descriptions of quality of life included in the HIV Plan focus on viral loads, viral suppression, and other health-related outcomes.[144] While these biomedical markers are components of the quality of life for PLHIV, they are not an acceptable proxy for a well-rounded understanding of well-being or quality of life.

Instead, the HIV Plan and other federal responses to HIV must value and create concrete metrics for emotional, mental, psychological, spiritual, and physical wellness - irrespective of viral suppression. Quality of life for PLHIV must be measured by a key set of metrics in any plans to address the HIV epidemic, and the federal HIV response must acknowledge that commitments to quality of life for people living with HIV must continue as long as people living with HIV are here. The human right to quality of life for people living with HIV, and the federal government's responsibility to assure that, does not end even when we get to zero new HIV acquisitions. Thus, quality of life for people living with HIV deserves its own pillars in the HIV Plan and the EHE, along with commensurate strategies, metrics, and indicators to measure success.

Quality of life is interrelated with social and structural drivers of the HIV epidemic and of worse health outcomes for some PLHIV. It is interlinked with and inseparable from upholding human rights for people living with HIV, as described above. For decades, far too little attention has been paid in the federal government's HIV response to the social and structural drivers of inequity. While the HIV Plan includes some of these important social and structural factors, such as systemic racism, safe and affordable housing, access to culturally competent, trauma-informed health care, and gender disparities, it could be strengthened by concrete commitments to strategies and solutions. The EHE is completely missing an explicit analysis of and commitment to social and structural drivers of inequity. Until these factors are addressed explicitly and with firm commitments, any plan to address the national HIV epidemic will be unsuccessful and will not adequately address the needs of PLHIV.

There is a lack of consensus in the academic and medical community on the specific dimensions of quality of life, but it is generally understood as being multifaceted and concerning a person's own perception of their well-being and level of functioning in important areas of their life.[145] There are various scales that have been utilized in measuring the quality of life of people living with HIV.[146] One omnipresent problem is that most of these metrics focus on biomedical markers, and inadequate research has been done on what quality of life means for people living with HIV beyond these markers.

Additional research is required to determine what scale and metrics are the best measure(s) of the quality of life for people living with HIV, with an understanding that this metric may be different for individuals who are Black, Indigenous, and other people of color; cisgender; transgender; sex workers; immigrants; and of different geographies, due to racism, poverty, homophobia, transphobia, and lack of language justice.[147]

Opportunities to Strengthen the Federal Domestic HIV Response for Quality of Life for People Living with HIV

Priorities that continue to arise in conversations with our PLHIV networks concerning quality of life include employment; economic justice; health care costs and quality; the availability of non-stigmatizing and high-quality sexual and reproductive health care for PLHIV; access to trauma-informed care and services; and ending enacted, internalized, interpersonal, community, and institutional stigma.

Any plan to end the HIV epidemic must center these priorities and include them as concrete metrics in its plan.

Recommendations for Issue Area 5 - Quality of Life for People Living with HIV

Recommended Agency, Federal Body, or Policy	**Recommended Action(s)**
Department of Health and Human Services	1. Promulgate regulations requiring private insurers to uphold the HIV Plan's minimum standard of care for all PLHIV. 2. Lead the creation of report cards[148] on the state of quality of life for PLHIV in the country and the quality of care provided by federally funded programs and services.
National Institutes of Health	1. Fund research into developing a standard quality of life assessment for people living with HIV focused on quality of life outside of biomedical indicators.
Centers for Medicare and Medicaid Services	1. Adopt the minimum standard of care developed in the HIV Plan and incorporate it into care provided by CMS.

HIV National Strategic Plan	1. Set a minimum standard for quality of life for PLHIV which includes: a. Opportunities for employment and education for all people living with HIV.[149] b. Increasing the ease of transferring benefits across jurisdictions. c. Access to long-term sustainable housing for people living with HIV.[150] This should include senior housing for aging PLHIV and housing for PLHIV with dependents. d. Services for people living with HIV should incorporate access to nutrition service programs, including SNAP.[151] 2. PLHIV who receive health care from any payer source should have a minimum standard of care[152] which: a. Is culturally relevant and affirms and funds the sexual and reproductive health care needs of people with HIV at all life stages and of all gender identities, including transgender women.[153] This should include reporting mechanisms which are easily understood by and communicated to people living with HIV; b. Provides mental health services and the choice of mental health provider to people living with HIV; c. Provides affordable health care coverage, where total health care costs (inclusive of premiums, medications, copays, etc.) do not exceed 9.83 percent[154] of the income of a person living with HIV; and d. Practices trauma-informed care, including screening and intervention for lifetime abuse and intimate partner violence, in HIV clinical and community-based settings. 3. Express support from the federal government for the repeal of HIV criminalization, which acknowledges the role it played in advancing these laws; education to state legislatures on their harms; and conditioning funding on their modernization or repeal. 4. The incorporation and study of accurate stigma metrics.[155] 5. Require that all materials on HIV-related services be translated into the primary languages spoken in the jurisdiction and incorporate translation services into clinical and supportive service settings for people living with HIV. 6. Incorporate quality of life surveys into federally funded clinical and supportive service settings, with the aim of using the data to connect people to additional support, including psychological, spiritual, and emotional support systems.

5A. Establishing a Strong Safety Net for People Living with HIV

Economic Justice and Employment for People Living with HIV

Economic justice does not have a set definition but can be understood as principles and practice that allow for PLHIV to live without negative employment or economic consequences related to their health status, disability, sex, gender or gender expression, sexual orientation, family responsibilities, and/or race or ethnicity.

Maintaining access to health care and economic stability can entrap PLHIV in poverty. Policies for ongoing eligibility for Supplemental Security Income (SSI)/Social Security Disability Income (SSDI), Medicaid/Medicare, AIDS Drug Assistance Programs (ADAPs), Housing Opportunities for Persons with AIDS (HOPWA), and other programs designed to improve health and well-being, are complex and serve as disincentives to employment for people living with HIV or other chronic health conditions and disabilities.[156] The lack of assistance to understand and navigate these policies can also serve as a disincentive or barrier to employment for enrolled PLHIV concerned about protecting their health and well-being and that of their families.

In addition, the lack of portability of benefits can prevent PLHIV from relocating to environments where they might thrive. PLHIV who are economically reliant on or choose employment receive little to no access to employment-related information, services, or resources to enable well-informed decisions about work or facilitate self-determined plans for employment and economic health and well-being.

Economic justice for PLHIV must also include a commitment to recruiting and training community members to join the expanded HIV workforce. PLHIV are the subject matter experts on programs that support PLHIV and are expert navigators. We encourage a creative approach to valuing lived experience as qualification for these positions beyond formal education requirements. When adding PLHIV to the HIV workforce, they must be at all levels of leadership, not simply relegated to the frontline staff, peer support staff, or testing and outreach.

Access for all PLHIV to non-discriminatory, non-stigmatizing employment-related information, services, and resources has not been developed in most of the country, nor prioritized by public health or workforce development systems, despite more limited access to disability benefits, and high rates of poverty, unemployment, and underemployment for PLHIV. The public health system response to HIV has deferred attention to employment needs of PLHIV to the workforce development system, which does not prioritize health and well-being strategies or outcomes, nor implement policies or training, to ensure effective, responsive service delivery based on understanding distinct needs and issues of priority populations disproportionately impacted by HIV.

Recommendations for Issue Area 5A - Economic Justice and Employment

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
White House/Office of the President of the United States	1. ONAP to be responsible for convening a federal and community workgroup including representation of the Employment and Training Administration (ETA) of the Department of Labor, the Department of Education, the Department of Housing and Urban Development, the Department of Justice, the Social Security Administration, the Centers for Medicaid and Medicare Services (CMS), HHS Health Resources and Services Administration HIV/AIDS Bureau (HRSA/HAB), PLHIV networks, and other community leaders to outline strategies to eliminate economic and employment inequities for PLHIV and facilitate self-determined transitions to work without risk to health and well-being.
HIV National Strategic Plan	1. Establish access to benefits counseling/advisement for PLHIV enrolled in or eligible for SSI/SSDI, Medicaid/Medicare, ADAPs, HOPWA, and other programs designed to improve health and well-being, for well-informed and well-supported employment-related decision-making and transitions of PLHIV allowing maximal protection of health care, financial, and housing supports. 2. Assign responsibility to the Social Security Administration (SSA), CMS, HRSA/HAB, and HUD Office of HIV/AIDS Housing (HUD/OHH) for collaborating with community leaders to evaluate program policies for impacts on considering and navigating employment transitions for PLHIV and for identification of updates needed to policies designed to reduce barriers and disincentives to working and optimize health and well-being. 3. Design portability of benefits between jurisdictions so PLHIV can more as needed or desired. 4. Require a formal HIV workforce recruitment and training program to hire PLHIV and commit to a targeted number or percentage of PLHIV in the HIV workforce. 5. Revise policy of the HRSA/HAB to allow direct service responses to employment needs of PLHIV within the Ryan White HIV/AIDS Program (RWHAP), recategorizing employment services as allowable for funding among RWHAP supportive services addressing core needs of PLHIV. 6. Ensure implementation of a RWHAP-centered community-led PLHIV employment initiative, with designated funding from the ETA, and ETA's collaboration in its implementation with HRSA/HAB. 7. Establish ongoing training in the AIDS Education and Training Centers (AETCs) of HRSA/HAB for HIV service providers on employment service delivery, linking and partnering with the workforce development and vocational rehabilitation systems, and interactions between work earnings and health care/treatment coverage, financial, and housing benefits.

Congress	1. Require SSA to update long-unchanged work incentive policies and calculations to increase the ability of PLHIV and other people with disabilities and chronic health conditions to attempt working with increased health coverage, financial, and housing security. 2. Require SSA to fund the establishment of accessible online information resources accurately reflecting policies applicable in each U.S. state and territory. 3. Allocate additional funds for SSA's Work Incentives Planning and Assistance (WIPA) program to more realistically scale up staffing proportionate to needs of PLHIV and other disabled SSI/SSDI beneficiaries for individualized in-person and remote benefits counseling/advisement, from considering work through transitions to employment. 4. Include designated funds to address employment needs of PLHIV through public health and workforce development collaboration in the upcoming reauthorization of the Workforce Innovation and Opportunity Act (WIOA).

Housing as a Human Right and Necessary Precursor to Care and Treatment for People Living with HIV

It has long been understood by PLHIV, researchers, activists, and policy makers that housing is a form of health care for people living with HIV.[157] Despite this knowledge, housing instability remains a primary concern for PLHIV,[158] as many federal housing programs are underfunded and under-resourced.

PLHIV are at a much higher risk of being unstably housed or homeless than the general population. In 2016, the U.S. Department of Housing and Urban Development (HUD) Office of HIV/AIDS Housing published data showing that an estimated 145,366 PLHIV in the United States, or about 12 percent of all PLHIV, have a current unmet housing need.[159] This data showed that 44 percent needed ongoing assistance to pay rent, 36 percent sought supportive housing placement, and 20 percent had short-term emergency assistance needs to secure or maintain housing.[160]

A lack of stable housing is not only an issue of a lack of shelter for PLHIV. Numerous studies have shown that it has a deleterious effect on the health outcomes for PLHIV, including mental health outcomes.[161] A lack of stable housing also affects a person's ability to obtain and maintain employment.[162]

These effects are not experienced equally by all PLHIV. Instead, there are stark differences in housing instability, and its effects, based upon an individual's race, age, and gender. People of transgender experience are more likely to be unstably housed than cisgender men and women.[163] Black, Indigenous, and other people of color are also more likely to be homeless in America when compared to the national average and white American.[164] In order to effectively implement any federal response to addressing the HIV epidemic and the health and equality of life for PLHIV, housing insecurity will need to be addressed.

Recommendations for Issue Area 5A - Housing

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
White House/Office of the President of the United States	1. Call for HOPWA to be funded at $600 million in the President's Budget Request. 2. Call for Increased funding for federal housing programs relied on by people living with HIV such as Housing Choice Vouchers, rental assistance, and subsidized housing in the President's budget request.
Department of Justice	1. Enforce the Fair Housing Act to address discrimination against women; immigrants; LGBTQ individuals; Black Indigenous, and other people of color; and people with criminal convictions.
HIV National Strategic Plan	1. Include concrete housing metrics in the implementation plan, such as: 90 percent of PLHIV are in long-term stable housing. 2. Include concrete commitments that people aging with HIV have access to senior housing.
Ending the HIV Epidemic Plan	1. Consider housing availability and create metrics and programs to increase housing access among people living with HIV in developing jurisdictional plans. 2. Address the quality of life metrics created by the HIV Plan in creating jurisdictional plans.

Food and Nutrition Security for People Living with HIV

Many PLHIV rely on federally funded programs to access essentials like food and nutrition services, often through the Supplemental Nutrition Assistance Program (SNAP). This can be demonstrated by membership data collected by Positive Women's Network - USA, which consistently indicates that between 40-50 percent of the women and people of trans experience living with HIV who are members of the organization depend on SNAP to feed themselves and their families.[165]

These food assistance programs are critical for PLHIV to receive good nutrition, which in turn supports overall health, helps with immune system function, and can help maintain a healthy weight, which helps with the absorption of HIV medicines. Reducing the stress associated with food insecurity also improves the overall quality of life for PLHIV. Further, a recent study showed that the rate of HIV diagnoses is associated with a state income limit for SNAP eligibility, meaning the higher the income limits a state imposes is related to higher numbers of HIV acquisitions.[166]

Currently, many SNAP eligibility requirements are harsh, and the benefits are insufficient. In 2018, SNAP benefits averaged only $1.40 per person, per meal.[167] Even the maximum benefit, which is the equivalent of $1.86 per meal, does not cover the cost of a meal in 99 percent of continental counties and Washington, DC.[168] Benefits at this level cannot support an individual's or family's nutritional needs. While the benefits are intended to be supplemental, many participants contend that the benefits levels are too low to assist them with purchasing food for the month.

SNAP is a program with very low rates of fraud, but its administrative burdens often make it so those who need the benefits cannot access them. While some of the harsh requirements have been relaxed during the pendency of the COVID-19 pandemic, more long term changes are required for the benefits of the program to be realized by everyone who needs them. These burdens include lengthy applications, high documentation requirements, in-person interviews, and the need to recertify or reapply to maintain benefits.

These requirements prevent some individuals who are eligible for SNAP from receiving them, though they could use the benefits to lift themselves and their families out of poverty. An example of this can be seen in a recent Michigan study, which found that half of SNAP recipients who lost their benefits during their first year of enrollment were still eligible for SNAP when they left the program.[169] These burdens and the inadequate benefits hinder a program which could be an important mechanism to improving the quality of life for PLHIV.

Recommendations for Issue Area 5A - Food and Nutrition Security

Recommended Agency, Federal Body, or Policy	**Recommended Action(s)**
Department of Agriculture	1. Account for local and regional costs of living in determining SNAP benefit levels. 2. Continue the SNAP extensions of the 3-month work requirement period implemented during the COVID-19 pandemic. 3. Incentivize states to remove additional administrative SNAP burdens and work requirements. 4. Simplify the administrative burdens of SNAP by continuing the elimination of in person visits, permitting online recertification, increasing waivers, telephonic benefits applications, and extending recertification periods. This could also be achieved by providing funding to states to receive the technology required for implementing telephonic benefit applications and online recertifications.
Congress	1. Repeal the ban on SNAP and TANF for individuals with felony drug convictions contained in 21 U.S. Code § 862a. 2. Increase SNAP's maximum allotment by 15 percent and raise the minimum benefit to $30 per month from its current level of $16 per month.

5B. Improving Health Care Access and Quality of Health Care for People Living with HIV

Health Care Access for People Living with HIV

About 50 percent of PLHIV in the U.S. are not receiving regular HIV-related care.[170] It is therefore unlikely that these individuals, and potentially more, are receiving other kinds of care they need, including mental health care, sexual and reproductive health care, and specialty care. A multitude of factors lead to this, but often, the prohibitive costs of health care, stigmatizing experiences in health care settings, and discrimination are to blame.

Twelve states have still not expanded Medicaid,[171] even given the incentives under the ACA and the recent COVID-19 relief packages. In states where Medicaid has been expanded, only 5 percent of people remain uninsured, compared to the 19 percent in states where Medicaid has not been expanded.[172] A majority of the states that have not adopted Medicaid expansion are in the South, where approximately 45 percent of all PLHIV in the United States reside.[173]

Even the Ryan White HIV/AIDS Program fails to adequately provide the wrap-around services that clients need to be successful and live full, healthy lives. Further, out-of-pocket costs for prescription medications[174] and copays for care visits can still be prohibitively expensive for PLHIV. Even with the benefits gained from the ACA, problematic health insurance practices, like copay accumulators,[175] are on the rise, which could also increase cost for PLHIV.

The federal response to HIV does not address the need for quality and non-stigmatizing sexual and reproductive health care for people already living with HIV.[176] People of all genders living with HIV require sexual and reproductive health care; unfortunately, this is one of the areas where people living with HIV suffer from the greatest stigma, lack of understanding, and discrimination from health care providers. High quality, non-stigmatizing sexual and reproductive health care for all PLHIV is crucial to ensure well-being. For transgender people living with HIV, finding gender-affirming care in a non-discriminatory setting is essential to health and well-being.[177] This is especially true as many states are currently undermining the rights of transgender individuals. Further, postnatal people who are living with HIV can face stigma and even criminalization for their choice to breastfeed. Access to abortion care, birth control, and other family planning tools are also severely restricted in many states. Culturally relevant, non-stigmatizing, and comprehensive sexual and reproductive health care is essential to the quality of life of PLHIV.

While the HIV Plan mentions trauma-informed care and service delivery models, no explicit commitments are mentioned, and it is not included in other areas of the federal response to HIV. It is well documented that people living with HIV live with trauma and its downstream effects at rates well above the general population. A lack of explicit commitments to providing care and services that are trauma-informed will lead to stigmatizing and harmful experiences for the PLHIV who access these care programs.

It is important to note that issues related to HIV related health care are not equally distributed among PLHIV. The brunt of these problems is borne by Black, Indigenous, and other people of color, LGBTQ individuals, immigrants, cisgender women, and transgender women living with HIV, who face co-occurring oppressions like racism, sexism, and economic oppression.

Recommendations for Issue Area 5B - Improving Health Care Access

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
HIV National Strategic Plan	1. Revise the definition of quality of care to include a quality of life metric and a standard of care that is easily understood by PLHIV. 2. Make explicit commitments to integrate trauma-informed service delivery for people living with HIV in all federal plans to end the HIV epidemic, such as mandatory trainings on trauma-informed approaches for clinicians, providers and administrators; data collection on rates of intimate partner violence, post-traumatic stress disorder symptoms, substance use, depression, stigma, social isolation; implementation and evaluation of trauma-informed primary care models in clinics serving people living with HIV; integration of evidence-based responses to PTSD into existing funded clinical services, including therapy, psychiatry, medication adherence, and substance abuse treatment; and fostering collaborations between organizations addressing violence and trauma and those providing care and services to people living with HIV. 3. Develop a minimum standard of care for people with HIV who receive health care from any payer source. Such a standard should be adopted by CMS as well as by the Ryan White Program and any other payers. The following components should be included: a. Culturally relevant care that affirms the sexual and reproductive health care needs of people with HIV at all life stages and of all gender identities, including transgender women. b. High-quality clinical care – including affordable, accessible medication and insurance payment in areas where Medicaid has not been expanded under the ACA. c. Trauma-informed care practices, including screening and intervention for lifetime abuse and intimate partner violence, in HIV clinical and community-based settings. d. Services that facilitate PLHIV access to care as needed, including: childcare, transportation, substance use and mental health services, and housing. e. Define and implement a standard of gender-responsive care for people with HIV that includes the above sets of services. Prioritize funding for models that meet this standard within programs, such as the Ryan White Program. 4. Acknowledge racial injustice as a driver of the epidemic and include these factors in the response. 5. Expand the response beyond biomedical solutions and consider the role of culture, structural drivers of health, and solving for root cause analysis.
White House/Office of the President of the United States	1. Support increased funding for the Ryan White HIV/AIDS Program to \$2.768 billion in FY 2022.[178] 2. Support universal health care plans, including Medicare for All.

Department of Health and Human Services	1. Remove barriers to accessing 75/25 waivers through the Ryan White HIV/AIDS Program. 2. Rescind 85 FR 29164, which expressly permits insurers to adopt copay accumulator adjustment policies (CAAPs), and implement a rule disallowing this practice.
Congress	3. Pass the HIV Epidemic Loan-Repayment Program (HELP) Act of 2021 4. Pass the Medicare For All Act of 2021 5. Pass the Equality Act of 2021

5C. Inclusion of Sexual and Reproductive Health and Rights for People Living with HIV

People of all genders living with HIV require sexual and reproductive health care; unfortunately, this is one of the sites where people living with HIV suffer from the greatest stigma, lack of understanding, and discrimination from health care providers. High quality, non-stigmatizing sexual and reproductive health care for all people living with HIV is crucial to ensure well-being and overall health. Yet, there is little mention in the HIV Plan ensuring quality and non-stigmatizing sexual and reproductive health care for people living with HIV, limited to how it pertains to raising awareness of HIV and improving integrated services.[179] The inclusion of the sexual and reproductive health and rights of people living with HIV is essential to ending the epidemic.

Ensuring High-Quality, Non-Stigmatizing, Trans-Inclusive, and Culturally Relevant Sexual and Reproductive Health Care for People Living with HIV

The first goal of the HIV Plan is "to prevent new HIV infections" by, in part, increasing awareness of HIV, increasing knowledge of HIV status, and increasing capacity of health care delivery systems to prevent and diagnose HIV.[180] To meet this goal, the HIV Plan notes the need to better utilize non-primary care providers, such as STD specialty clinics, Title X family planning sites, and OB-GYN visits.[181] We echo the need to utilize opportunities and to increase competency of the public health workforce in providing care for people living with HIV, especially to people who may not have regular access to a primary care provider for whom these encounters may be one of their rare entry points into the health care system.

But more than just utilizing these providers as ways to diagnose and prevent HIV, the HIV Plan should prioritize the overall sexual and reproductive health needs of people living with HIV, regardless of viral suppression. Sexual health, sexual pleasure, and reproductive health care and rights are cornerstone human rights[182] which must be a priority in the HIV response. It is not enough to increase testing and awareness in sexual and reproductive health care settings. The HIV Plan must consider the distinct sexual and reproductive health needs of people living with HIV. Also, cisgender women living with HIV who are receiving HIV-related medical care frequently are not offered sexual and reproductive health services or are referred elsewhere, even though women living with HIV are at elevated risk for gynecological complications.[183]

For transgender people living with HIV, it is especially important that gender-affirming care is provided and that providers and clinicians are well-versed on their options and rights. Transgender people face high rates of discrimination, stigma, and lack of trans-competent care in health care settings. According to the National Transgender Discrimination Survey, of surveyed participants, one in three transgender people delayed or avoided preventive health care out of fear of discrimination or disrespect.[184] Moreover, in the reproductive health care context, in a study of obstetrician-gynecologists, 80 percent had no trans-specific health care training in residency and only 33 percent reported feeling comfortable in providing care to transmasculine patients.[185]

Addressing Breast/Chest-feeding for People Living with HIV

The HIV Plan does not address breast/chest-feeding anywhere, although it does discuss HIV care as it relates to pregnant women[186] on two occasions.[187] These discussions focus on testing pregnant people for HIV, on which the health care system already receives a high rating,[188] and biomedical research into tools to prevent both HIV and pregnancy in women. The HIV Plan ignores and fails to advance whole swaths of the experience that must be navigated by people living with HIV who would like to become pregnant and parent.

Choices on how parents feed their infants are complex and multifaceted. People who parent should be given the full range of options, and a complete understanding of the risks and benefits of each, prior to making these decisions. In other countries, PLHIV are not discouraged from breast/chest-feeding; rather, they are educated on their options to do so safely. Yet, the CDC discourages PLHIV from breast/chest-feeding and has not provided guidance to medical professionals on ways to assist patients who would like to breast/chest-feed their children.[189] We know PLHIV can have healthy, HIV-negative babies, and are capable of making informed decisions about breast/chest-feeding.[190] However, they must be given support and information from their care team. Further, they should not fear criminalization or interventions from medical professionals or child protection systems in response to how they choose to feed their children.

These inadequacies in our systems of navigating pregnancy and breast/chest-feeding disproportionately affect Black and Latinx women, transgender, and gender non-conforming people, who acquire HIV at higher rates than the rest of the country and contend with the intersecting oppressions of racism, stigma, and sexism in encounters with the health care system. They face higher maternal mortality rates, and once they have children, BIPOC individuals are also more likely to be limited in options of how to feed their children and steered away from breast/chest-feeding. The HIV Plan must recognize the impact that racial health disparities, including structural racism, and poverty has on options PLHIV have children and to breast/chest-feed their children.

Recommendations for Issue Area 5C - Sexual and Reproductive Health and Rights

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
Department of Health and Human Services	1. Finalize and implement the proposed rule, "Ensuring Access to Equitable, Affordable, Client- Centered, Quality Family Planning Services," RIN 0937-AA11, which would strengthen the Title X family planning grant program and reverse the domestic gag rule. 2. Fully integrate comprehensive sexual and reproductive health care throughout the Ryan White Program. 3. Work with networks of people living with HIV to develop HIV-related guidelines on breast/chest-feeding to ensure they are up to date, reflect best practices and complexities of child feeding, and are consistent across disciplines; develop comprehensive postpartum guidelines for people living with HIV.[191]
National Institutes of Health	1. Develop and promote a research agenda on breast/chest-feeding that leverages existing findings, seeks novel applications of relevant data, and addresses knowledge gaps. 2. Partner with other agencies to disseminate research findings in an accessible way to providers and people living with HIV.
HIV National Strategic Plan	1. Include goals and metrics that focus on improving the sexual and reproductive health of PLHIV, including metrics for increased rates of recommended second Pap smear screening for newly diagnosed women, counseling on fertility desires and intentions, and increased rates of screening for intimate partner violence among women living with HIV in care. 2. Support informed consent standards that accurately and fully inform people of the implications of transition-related care, regardless of age, gender, or gender expression. 3. Discuss and fund research into safe practices for people living with HIV to breast/chest-feed children.
Ending the HIV Epidemic Plan	1. Require jurisdictions to create and provide sexual and reproductive health care guidance for providers to deliver to people living with HIV which includes information on how to access transition-related care, pregnancy care, breast/chest-feeding care, and contraceptive care. 2. Require jurisdictions to fund programs for providing comprehensive, culturally competent sexual and reproductive health care to people living with HIV, such as training programs for providers and ways for people living with HIV to access funds to pay for transition-related care, pregnancy care, breast/chest-feeding care, and contraceptive care. 3. Require jurisdictions to take a firm stance against the criminalization of breast/chest-feeding for people living with HIV and to take affirmative steps to educate child welfare agencies within the jurisdiction on the science around people living with HIV breast/chest-feeding.

Congress	1. Pass the Real Education and Access for Healthy Youth Act of 2021 2. Pass the Women's Health Protection Act of 2021 3. Pass the Equal Access to Abortion Coverage in Health Insurance (EACH) Act of 2021 4. Pass the Abortion Is Health Care Everywhere Act of 2021

Endnotes

1 *See, e.g.,* U.S. People Living with HIV Caucus [hereinafter HIV Caucus], *Opportunities and Mechanisms for Involving People Living with HIV/AIDS in the Nat'l HIV/AIDS Strategy's Implementation* (July 2011), https://drive.google.com/file/d/1ryFJk-akJQgFBiMx-hkc-6widiME-2mf-/view; HIV Caucus, *Moving Towards Positive Health, Dignity and Prevention* (July 2011), https://drive.google.com/file/d/1xv5K3eVKtcOc-UVoCz-tVBkvYCisSfkM/view.

2 *See generally,* Country and Regional Operational Plans, U.S. Dep't of State, https://www.state.gov/country-operational-plans (last visited June 24, 2021).

3 Elizabeth Guo et al., *Eliminating Coverage Discrimination Through the Essential Health Benefit's Anti-Discrimination Provisions,* 107 Am. J. Pub. Health 2 (2017), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5227931/.

4 Jennifer Kates & Lindsey Dawson, *Insurance Coverage Changes for People Under the ACA,* Kaiser Family Foundation (2017), https://www.kff.org/health-reform/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/.

5 Michael J. Mugavero et al., *Health care system and policy factors influencing engagement in HIV medical care: piecing together the fragments of a fractured health care delivery system,* 52 Clinical Infectious Disease, suppl. 2, S238, S238-39 (2011), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3106258/.

6 Off. of Nat. AIDS Pol'y, Exec. Off. of the President, National HIV/AIDS Strategy (2010) [hereinafter *National Strategy*], hivgov-prod-v3.s3.amazonaws.com.

7 *Id.* at 9.

8 U.S Dep't of Health and Human Services, 12 Cities Strategy, https://www.hiv.gov/sites/default/files/NHAS-HHS-12.pdf (last visited June 24, 2021).

9 Off. of Nat. AIDS Pol'y, Exec. Off. of the President, National HIV/AIDS Strategy Updated to 2020 (2015) [hereinafter *Updated National Strategy*], https://obamawhitehouse.archives.gov/sites/default/files/docs/national_hiv_aids_strategy_update_2020.pdf.

10 *Id.* at 8-11.

11 Off. of Infectious Disease and HIV/AIDS Pol'y, *What Is Ending the HIV Epidemic in the U.S.?*, HIV.gov (June 2, 2021), https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview.

12 Off. of Infectious Disease and HIV/AIDS Pol'y, *Key Strategies in the Plan,* HIV.gov (May 8, 2020), https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/key-strategies.

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150 For a more complete discussion of how to achieve housing goals, *see infra*, Issue Area 5A, pp.41-42.

151 *See infra*, Issue Area 5A, pp. 42-44 , for more on providing nutrition services for people living with HIV.

152 For more information on how to achieve these health care metrics, *see infra*, Issue Area 5B, pp. 44-47.

153 For more on what sexual and reproductive health care needs entail, *see infra*, Issue Area 5C, pp.47-51.

154 IRS Rev Proc. 2020-36 states that beginning January 1, 2021, the ACA 2021 affordability threshold will be 9.83%. This number should be adjusted for the quality of life standard each time the IRS alters its own affordability thresholds. Further, affordability should only be defined as total household income and should not be defined to include other investments or savings.

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https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics.

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ROOTED & RISING

2019-2020
IMPACT REPORT

POSITIVE WOMEN'S NETWORK
USA

artwork by Megan Smith/Repeal Hyde Art Project

A MESSAGE FROM OUR CO-EXECUTIVE DIRECTORS

Greetings PWN family!

2019 and 2020 were probably the most unpredictable and challenging years of PWN's herstory yet. We are overwhelmed with grief for everything our communities have been through and simultaneously grateful for the many ways our base mobilized to demand health care, full human rights, immigrant justice, and Black liberation.

In the face of a global pandemic, a racial uprising, increasing white supremacist violence, and what can only be described as a toxic presidential election cycle, PWN members organized and participated in mutual aid programs, Black Lives Matter organizing, text banks and phone banks, and immigrant solidarity events. We won on a number of issues: protecting abortion access and expanding paid family medical leave in Colorado, enhancing police accountability measures in Philadelphia, and advancing HIV decriminalization efforts in multiple states. Throughout all of this, we deepened our political education work on race and gender while transitioning to a co-executive director model.

Our destinies are bound together. When women and transgender people living with HIV are safe and free, all of us will be safe and free. We are so grateful for your support.

In sisterhood, solidarity, and until liberation,

Venita Ray

Venita Ray and Naina Khanna
Co-Executive Directors

BOARD OF DIRECTORS

Pat Migliore, co-chair

LaTrischa Miles, co-chair

Bré Anne Rivera, vice chair

Tana Pradia, treasurer

Nicole Seguin, secretary

Grissel Granados

Kathleen Griffith

Chunnika Hodges

Lisa Johnson-Lett

Octavia Lewis, MPA

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Rica Rodriguez

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Tyler Barbarin, *policy associate*

Barb Cardell, *training director*

Breanna Diaz, *policy director*

Kelly Flannery, *civic engagement coordinator*

Tiommi Luckett, *communications & training assistant*

Jennie Smith-Camejo, *communications director*

Evany Turk, *national field organizer*

Allie Watson, *If/When/How legal fellow*

POSITIVE WOMEN'S NETWORK-USA AT A GLANCE

Leadership Development

TRAINED 20,000+ MEMBERS & ALLIES

◆

TRAINED 50 WOMEN AND TRANS PEOPLE LIVING WITH HIV ON VOTER ORGANIZING

Advancing Racial, Gender & Economic Justice

PAID 123 PEOPLE LIVING WITH HIV

◆

LAUNCHED A TRAINING OF TRAINERS PROGRAM FOR TRANSGENDER WOMEN OF COLOR

Narrative Shift

OVER 50 WOMEN LIVING WITH HIV QUOTED OR PROFILED IN 100+ ARTICLES IN 40+ MEDIA OUTLETS

Organizing & Basebuilding

TEXTED & CALLED HALF A MILLION VOTERS

◆

FOSTERED & SUPPORTED 300 HIV VOTER ORGANIZERS

Policy

SUPPORTED HIV DECRIMINALIZATION CAMPAIGNS IN FL, GA, MO, NV, SC & VA

◆

MOBILIZED FOR LEGISLATIVE VICTORIES IN AL, CO & TX

2019-2020 HIGHLIGHTS: BUILDING POWER

PWN prioritizes building long-term power in communities of women and trans people most impacted by the HIV epidemic: Black people and people of color, especially in the U.S. South, and low-income folks.

Our strategies to do this include grassroots organizing and basebuilding, leadership development, and running issue-based and electoral engagement campaigns.

IN 2019 AND 2020 WE:

NURTURED AND SUPPORTED LEADERSHIP

PWN built and supported leadership development through intensive skills building and mentorship programs, including through

- our flagship year-long **PWN Policy Fellowship for Women Living with HIV**
- **Project SWARM** (Southern Women's Advocacy Response Mobilization), a regional organizing space for HIV advocates in the South

BUILT POWER AT THE BALLOT BOX AND BEYOND

PWN ran **integrated voter engagement activities** in Colorado, Georgia, Pennsylvania, and Texas, including:

- **voter registration** and education
- advocacy to **protect voting access**
- **outreach on ballot initiatives** that would restrict abortion rights, expand paid family medical leave, and expand police accountability.

In the process, **we nurtured a growing community of over 200 HIV voter organizers**, who deepened their understanding of political processes and are prepared to hold elected leaders accountable on issues affecting people living with HIV.

SPOTLIGHT:

PWN's Houston chapter, H-Town Power, has built a powerhouse. They launched the Texas Strike Force in 2019, a cross-movement coalition led by PWN members that tracks and responds to legislation and state agency decisions impacting our communities.

H-Town Power built statewide momentum on health care, reproductive rights, voting rights, and LGBTQ rights legislation by mobilizing community members and allied organizations.

In 2020, they seamlessly integrated electoral organizing, **reaching 125,000 Black and Latinx Harris County residents** to share critical information about voter registration, early voting, and election day voting through a robust phone and text bank operation. **They made 27,000 calls to voters, registered 350 people, and reached over 12,500 people on social media.**

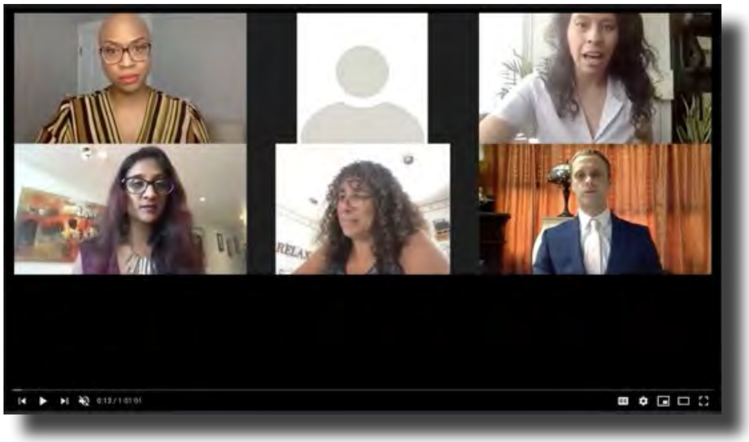
Through this work, H-Town Power has built deep relationships with community members and lawmakers along with a growing base, and is now mobilizing for the 2021 legislative session.

2019-2020 HIGHLIGHTS:
BUILDING POWER

ADVANCED INTERSECTIONAL POLICY SOLUTIONS

PWN members and staff worked tirelessly to advance **intersectional policy solutions grounded in lived experiences** of our base. For example:

- When the city of Atlanta mismanaged Housing Opportunities for Persons with AIDS (HOPWA) funds and put our people at risk of eviction, **we jumped into action with coalition partners to call out the city's failures, demand reform, and ensure participants remained securely housed.**
- We have **fostered a national conversation on molecular HIV surveillance** and demanded attention to structural determinants of health in the HIV National Strategic Plan.
- In 2020, PWN and our movement partners **launched the Health Not Prisons Collective to end carceral responses to public health** and elevate the need for a racially just HIV decriminalization response.



PWN's policy director and co-executive director hosted a briefing on HIV and covid criminalization for Rep. Ayanna Pressley in spring 2020.

SPOTLIGHT: PWN COLORADO

PWN's Colorado chapter has been a leader in grassroots organizing and legislative advocacy for years. The key to their sustainability is leadership development: supporting new advocates to step into leadership roles while allowing seasoned leaders to step back.

PWN Colorado successfully organized to pass comprehensive sexual health education and to ban "trans panic" as a defense during their 2019 legislative session.

Following PWN's 2019 Electoral Organizing Bootcamp, PWN Colorado began organizing for groundbreaking police reform, an equitable tax code, health care access, and LGBTQ rights during their 2020 state legislative session.

They dramatically shifted their legislative and electoral organizing tactics in response to the coronavirus pandemic and the uprisings for Black lives that followed the police murder of George Floyd.

The immense emotional, psychological, and economic toll on their communities led them to focus on mutual aid and harm reduction.

PWN Colorado integrated voter engagement into street outreach, racial justice protests, teach-ins, and other community events. They ran a full get out the vote program, including hundreds of hours of phone banks, text banks, and other activities to educate, register, and mobilize voters.

Their work helped Colorado win big on two ballot initiatives: defeating a proposed abortion restriction and winning statewide paid family leave.

2019-2020 HIGHLIGHTS: STRENGTHENING OUR CORE

PWN's commitment to racial, gender and economic justice have included internal reflection and external field building work to strengthen our practice of these principles.

The COVID-19 pandemic, a political environment hostile to our communities, and a tumultuous election season shaped the context of our work in 2019 and 2020.

IN RESPONSE WE:

SUPPORTED WOMEN & PEOPLE OF TRANS EXPERIENCE LIVING WITH HIV IN TIMES OF CRISIS

We moved beyond advocacy to support the urgent social, physical, and financial needs of our members and communities by:

- launching **PWNCares Sister Circle, a virtual support group** and online community space
- starting a biweekly **online crafting circle**
- creating an **emergency response fund to directly resource PWN members** experiencing financial instability
- launching a **Black Women's Healing Justice Collective**
- **creating "safety pods"**: regional groups of PWN members and allies that communicate regularly for safety, support, and resources

PWN cares

SISTER CIRCLE

FIRST MEETING

THURS. 3/26

5PM EDT/2PM PDT

VIRTUAL SUPPORT GROUP

Register at bit.ly/pwn-support

POSITIVE WOMEN'S NETWORK

pwn-usa.org

PWN cares

Sister Circle

Mental Health Matters

Monday, Dec. 14

12pm EST/9am PST

Join a lively conversation about how we can take care of our mental health and why it's more important than ever, with:

- Alicia Diggs
- Shadawn McCants
- Bré Rivera
- Masonia Traylor

Register at bit.ly/pwncares-healthy

POSITIVE ACTION

POSITIVE WOMEN'S NETWORK

2019-2020 HIGHLIGHTS:
STRENGTHENING OUR CORE

PWN Colorado leader Shannon Robinson led a march for racial justice in summer 2020 in rural Colorado.

ELEVATED OUR COMMITMENT TO RACIAL JUSTICE

We elevated our racial justice commitments through:

- active participation on the **steering committee of HIV Racial Justice Now**
- White Folks of PWN Dismantling Racism, an **anti-racism study and practice group** for white members, staff, and board
- helping to **launch a racial justice index committee** at the AIDS United Public Policy Council
- working in collaboration with Funders Concerned About AIDS to **elevate a racial justice lens in HIV philanthropy**
- **creating a Black staff workgroup** to support PWN's Black staff personally and professionally and create a space for them to generate ideas for ways to elevate our racial justice commitments internally and externally, such as 2021's successful Celebrate & Honor Black Women in the HIV Movement Day.

ELEVATED OUR COMMITMENT TO TRANS LIBERATION

PWN has always been trans-inclusive. We intentionally elevated our commitment to trans rights, justice, and liberation by **launching the R.I.S.E. (Resist, Inspire, Sustain Through Education) Training Academy to train, prepare, and coach trans women of color living with HIV** to be certified PWN trainers.

- Eight participants have graduated from the program.
- Participants received stipends for their participation.
- We have also produced webinars and fact sheets on trans rights, safety, and justice, and developed an internal training on trans justice that is required for all PWN board and staff members.

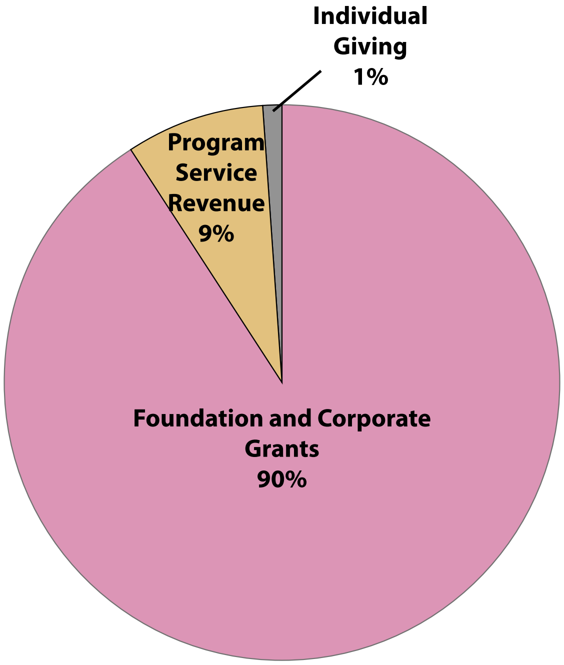
RISE graduates Queen Hatcher Johnson, Angela Hunt, Keleka Kaneaiakala, and Natalia Pabon

During this two-year period, PWN's revenue and staff grew significantly. PWN provided paid opportunities to more than 175 people living with HIV, the majority of whom were Black people, non-Black people of color, and low-income people, including through employment, honoraria, stipends, and contracts.

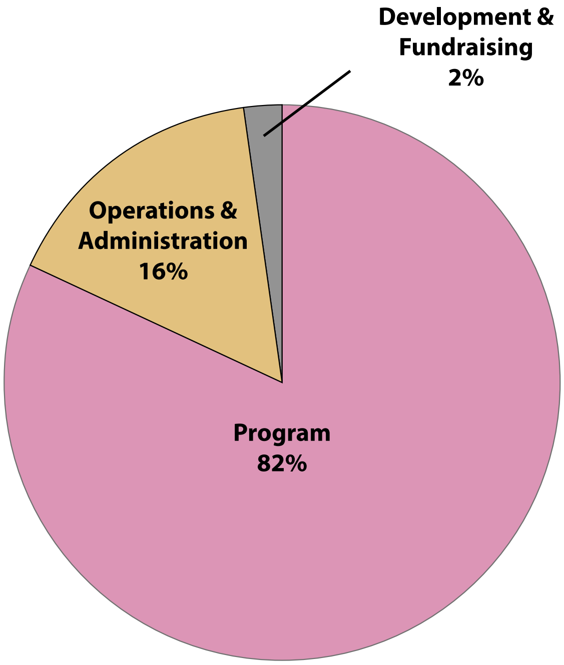
** PWN's fiscal year runs July 1-June 30. Revenue includes multi-year grants.*

2019 FINANCIALS

Revenue: $1,230,000*

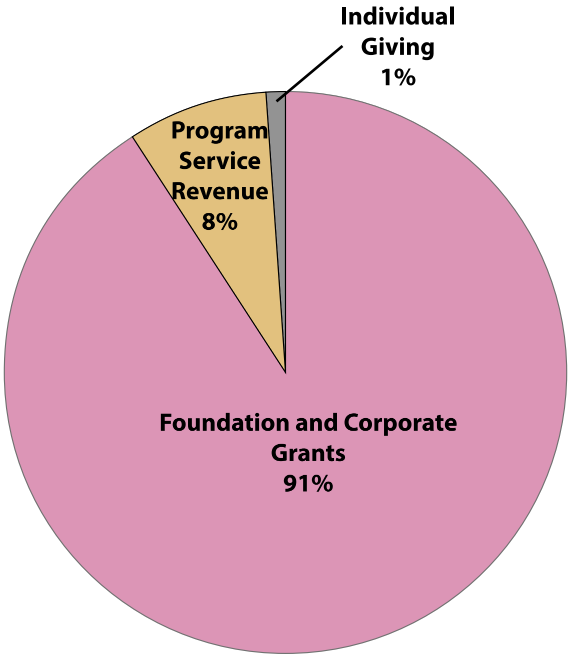


Expenditures: $1,002,693

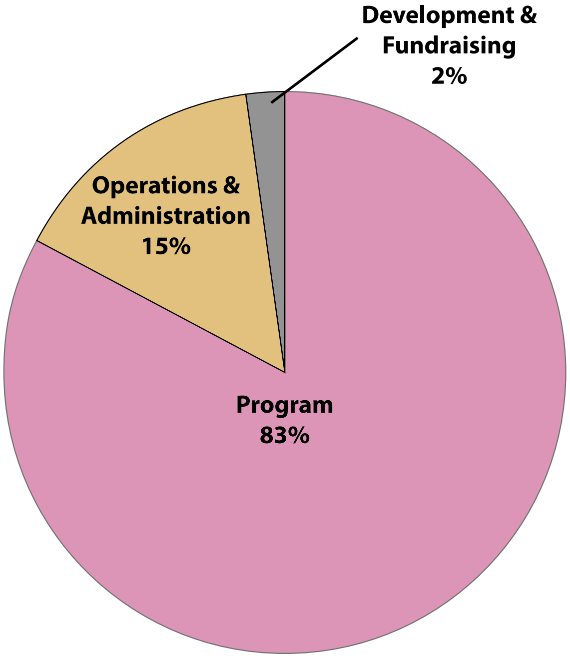


2020 FINANCIALS

Revenue: $1,207,308



Expenditures: $1,209,131



THANK YOU!

Our funders are essential partners; our work together is based in shared vision and values and grounded in relationships imbued with respect and trust and a commitment to a deep collaboration to achieve a world where women and people of trans experience livng with HIV thrive, free from all forms of stigma, discrimination, and oppression.

We are deeply grateful to the funders whose generous investment in our work has made our tremendous trajectory possible.

AIDS Healthcare Foundation

AIDS United

Elton John AIDS Foundation

Emory University

Ford Foundation

Glaxo SmithKline/ViiV Healthcare

Gilead Sciences

Groundswell Fund

HIV Justice Worldwide*

If/When/How

Levi Strauss Foundation

MAC AIDS Fund

Neo Philanthropy

Simmons Foundation

Wellspring Philanthropic Fund

** Denotes subcontract*

Positive Women's Network-USA is proud to be fiscally sponsored by Movement Strategy Center (MSC), a 501(c)3 organization that works to build a progressive movement by increasing the capacity of individuals, organizations, alliances and sectors to be more strategic, collaborative and sustainable. MSC's full audited financials can be viewed at https://www.guidestar.org/profile/20-1037643.

THANK YOU!

We are so thankful for our 2019-2020 donors. Over two years, our individual donors have steadily grown to more than 150 strong! Because of your support and investment, we have the flexibility to respond rapidly to emerging needs and grow our leadership base of women living with HIV.

This donor list reflects all gifts made between January 1, 2019 and December 31, 2020. If your name appears incorrectly or your name is missing, please get in contact with Naina Khanna at naina@pwn-usa.org

Gabriel Arkles
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Rose Works
Joey Wynn
ayelet yonah
Samuel Young

THANK YOU!

To our members, allies, accomplices, and partners: We see you. We honor you. And we will keep fighting with and for you.

2020 was an exceptionally difficult year, and we are grateful to you for showing up, speaking out, organizing, protesting, and causing good trouble with us when you could.

PWN chapter officers, state leads, and membership base contacted hundreds of thousands of voters and realized the power of the HIV vote.

Our policy fellows and spokespeople have elevated the voices, analysis, and priorities of women living with HIV at policy tables and in the media.

Our policy coaches, strategic advisors, and key partners have provided important trainings, had our back in coalition spaces, and generously mentored our members and staff.

PWN's founders, board members—past and present—have dedicated countless hours to building a robust, accountable, and sustainable organization.

Every year there are more people to thank because every year, you bring new people into our social justice orbit. We couldn't do it without you.

PWN works in alignment with movement partners. We are proud to serve as an active member of the Act Now End AIDS Coalition, the AIDS United Public Policy Committee, the Black United Leadership Institute, the Health Not Prisons Collective, HIV Justice Worldwide, HIV Racial Justice Now, the Radical Communicators Network, and the U.S. People Living with HIV Caucus.

We also work with state coalitions and advocates on the ground to enact meaningful change that will impact women and trans people living with HIV, including Decrim Sex Work California, the Dallas-Fort Worth HIV Taskforce, the Florida HIV Justice Coalition, the ECHO-VA Coalition, and Missouri Decrim.

These are just a few of our generative, collaborative partnerships. There are more, and we look forward to many more years of sharing in thought leadership and vision.

PWN state leads and member spokespeople at a communications and organizing training in Washington, DC, in September 2019

POSITIVE WOMEN'S NETWORK USA
pwn-usa.org

Positive Women's Network - USA envisions a world where all self-identified women living with HIV can live long, healthy, and dignified lives, free from stigma, oppression and discrimination.

Since PWN was founded by 28 diverse women living with HIV in 2008, including women born outside the U.S., women of trans experience, and monolingual Spanish speakers, we have grown to be a political home and community of solidarity and support for thousands of people in more than 20 states. PWN's members and leadership are women and people of trans experience living with HIV; the majority are low-income, Black, and/or live in the U.S. South. Beyond our membership, we organize a broad base of allies and accomplices who share our priorities and values.

With regional chapters organizing in seven states and state leads in an additional nine states, numerous training and leadership development programs, a virtual support group, online workgroups, webinars, and online community conversations, there are many ways for women living with HIV to get involved!

To learn more, get involved, or support our work, please visit our website at pwn-usa.org

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Racial Justice in HIV Philanthropy Guiding Principles

November 2021

FCAA

ACKNOWLEDGMENTS AND DEDICATION

Funders Concerned About AIDS (FCAA) thanks HIV Racial Justice Now for partnering with us in our work on racial justice since 2018. These efforts began with a plenary session at the 2018 AIDS Philanthropy Summit entitled, “We have nothing to lose but our chains - Toward a Racial Justice Framework for the HIV Justice Movement,” followed by further outreach to broader philanthropy, and ultimately, to the development of these principles.

Thank you to the FCAA Racial Justice Working Group for providing both the inspiration for, and valuable input into, this important project. We also wish to thank Christine Campbell, CMConsulting, for leading the development of these principles.

In the spirit of language justice, we would also like to acknowledge and thank José Romero (designsbyjar@outlook.com) for the translation of these principles into Spanish.

Finally, we would like to acknowledge the contributions of Marco Castro-Bojorquez, who helped initiate this effort in body, and continues with us in spirit. We dedicate these principles to his memory.

INTRODUCTION

Structural racism and social determinants of health, such as poverty, homelessness, and less access to healthcare, have long fueled the HIV epidemic within communities of color in the United States. In 2018, Black/African American people accounted for 13% of the U.S. population, but 42% (16,002) of the 37,968 new HIV diagnoses in the U.S. and dependent areas.[i] In particular, African American gay men and men who have sex with men (MSM) bear the brunt of the epidemic. African American gay/bisexual/MSM represent less than 1% of the total U.S. population, but one in four new HIV diagnoses infections nationally.

While this data is stark, it hides another critical issue: the lack of consistent access to and reporting data on HIV in transgender women. This often inflates MSM-related data and masks the lived reality of transgender women of color living with HIV.

Following the 2020 explosion of the COVID-19 crisis, in parallel with the global #BlackLivesMatter protests of state-sanctioned violence against African Americans, there has been an increased, public emphasis on racial equity and a slow movement towards racial justice.[1] However, according to the Philanthropic Initiative for Racial Equity (PRE), the philanthropic landscape for this work was already under resourced: in 2018 only six percent of philanthropic dollars supported racial equity work, and even less – just one percent - supported racial justice work.[ii]

Within the HIV context, recent data from Funders Concerned About AIDS (FCAA) shows that only 14% ($30 million) of U.S.-based HIV-related philanthropy supported Black, Indigenous, People of Color (BIPOC) communities in 2019.[iii] [2] The same communities that, according to the Centers for Disease Control and Prevention, represent close to 70% of people living with HIV in the U.S.

As we examine the distinctions between racial equity and justice, we see that while there may have been increased emphasis, funding opportunities have not necessarily addressed racial equity by explicitly naming BIPOC communities in their intent and strategy, and an inevitably smaller portion of this funding is distributed using a racial justice framework.

In response to the clear gap between resources, as well as recent calls for philanthropic anti-racist action,[3] the FCAA Racial Justice Working Group developed a set of racial justice guiding principles that aims to change how funders approach philanthropy.

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[1] For definitions of racial equity and racial justice, please read the appendix on pages 5 & 6.

[2] FCAA's methodology defines BIPOC communities as African Americans, Latinx, Asian/Pacific Islanders, Indigenous/American Indians, and Alaska Natives.

[3] Defined as strategies and tactics meant to counter racial prejudice, systemic racism, and the oppression of specific racial groups.

PRINCIPLES

In service to that goal, FCAA calls for HIV philanthropy to commit to the following principles and develop metrics to hold themselves accountable to anti-racist funding that specifically dismantles structural racism, increases funding for racial equity, and moves us towards racial justice in the following ways:

Governance

- Commit to having BIPOC with lived experience in positions of power:
  - On our Boards of Trustees, staff, hiring panels
  - In key organizational leadership roles
  - On our resource allocation decision-making bodies.
  - As part of our strategic planning sessions
  - As reflected in our human resources and program operations

Grantmaking Practices and Capacity Building[4]

- Provide flexible, long-term, core funding opportunities for BIPOC-led communities and community-based organizations
- Employ participatory grantmaking approaches where BIPOC:
  - Are engaged in identifying and prioritizing funding focus areas
  - Participate in the creation of funding opportunity notices of funding availability
  - Participate in the creation of criteria for selection
  - Participate in the decision-making process in determining awards
  - Support Intermediary funders who are better positioned to respond flexibly and quickly to the needs of the BIPOC communities
  - Identify and advance alternative metrics to measures of success and impact of the work being done in communities using quantitative and qualitative information to measure impact.
- Seek advice on funding priorities from BIPOC-led organizations
- Increase funding opportunities to BIPOC-led organizations
- Increase multi-year access to funding by streamlining onerous grant requirements, and processes.
- Provide capacity building technical assistance to BIPOC-led community-based organizations, enhancing their ability to compete, secure, and manage funding opportunities.
- Provide executive coaching and mentorship to BIPOC leaders, supporting their leadership and enhancing their ability to be effective in white dominant/supremacist settings.
- Identify or establish a pipeline process with placement opportunities for BIPOC leaders to hold positions of power, such as board openings, for those who have received capacity building.
- Advance succession planning to ensure the cycle continues and we are continually supporting new and emerging BIPOC leadership.
- Support all phases of building sustainable organizations, including but not limited to policy fellowships, mentoring, non-profit start-up, grant writing, Strategic planning, technology support, marketing, communications, evaluation, financial management, and advocacy.

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[4] The National Committee for Responsive Philanthropy's (NCRP) definition of effective grantmaking for marginalized communities "includes only giving that name marginalized people explicitly in its intent or strategy." NCRP also highlights that this explicit naming is directly tied to both progress and accountability for foundation equity goals.

Coordination and Collaboration

- Work with public and private funders to coordinate resources to promote comprehensive systemic resource allocation, promoting racial equity across the HIV service delivery system.
- Work across sectors that touch the HIV community to promote seamless access to care, treatment, prevention, and supportive services. Sectors include but are not limited to:
    - Humanitarian aid
    - Housing
    - Environmental
    - Medical
    - Mental health
    - Technology
    - Public health
    - Public Safety
    - Human rights
    - Social justice
    - Health equity
    - Reproductive justice
    - Immigrant rights
    - Workforce development
    - Gender equity
    - Racial justice

Philanthropic Advocacy

- Use our power and influence as funders and intermediaries to:
    - Lift up the long-term work that BIPOC-led communities and community-based organizations are doing to address structural racism, inequality, and discrimination.
    - Connect communities and community-based organizations to national, state, and local policymakers.
    - Highlight disparities in funding for BIPOC communities, particularly for those intersectional communities (e.g. gay, bisexual and other men who have sex with men; people living with HIV; cisgender women; people of trans experience; people who have experienced erratic housing; people with mental health issues; people who use drugs; sex workers).
    - Elevate social and racial justice approaches to philanthropy.
    - Increase multi-year funding for political education, advocacy, and leadership development.
- To ensure that Racial Justice remains a priority, funders also commit to:
    - Develop and sustain an industry workgroup made up of individuals and organizations from most impacted communities to continue to provide feedback and recommendations as to progress.
    - Listen to what is needed on the ground from people on the ground and will critically reflect on how to work better in the service of the communities we serve.

APPENDIX: DEFINITIONS AND ENDNOTES

To root the Racial Justice in HIV Philanthropy Guiding Principles in a common understanding, we have provided definitions – and sources there of – of racial equity and racial justice. Further yet, we have provided a definition on how these terms can be defined within grantmaking processes and data.

Broad Definitions:

RACIAL EQUITY

1. Racial equity is the condition that would be achieved if one's racial identity no longer predicted how one fares in a statistical sense. When we use the term, we are thinking about racial equity as one part of racial justice, and thus we also include work to address root causes of inequities, not just their manifestation. This includes eliminating policies, practices, attitudes, and cultural messages that reinforce differential outcomes by race or fail to eliminate them.
2. A mindset and method for solving problems that have endured for generations, seem intractable, harm people and communities of color most acutely, and ultimately affect people of all races. This will require seeing differently, thinking differently, and doing the work differently. Racial equity is about results that make a difference and last.

   Source:

   1. Center for Assessment and Policy Development.
   2. OpenSource Leadership Strategies.

   Related Resources: Racial Equity Tools. Available online: *www.racialequitytools.org/resources/fundamentals/core-concepts/racial-equity*

   Location: FUNDAMENTALS / Core Concepts

RACIAL JUSTICE

1. Racial Justice is the systematic fair treatment of people of all races, resulting in equitable opportunities and outcomes for all. Racial justice is not just the absence of discrimination and inequities but also the presence of deliberate systems and supports to achieve and sustain racial equity through proactive and preventative measures.
2. Operationalizing racial justice means reimagining and co-creating a just and liberated world and includes:
   - understanding the history of racism and the system of white supremacy and addressing past harms,
   - working in right relationship and accountability in an ecosystem (an issue, sector, or community ecosystem) for collective change,
   - implementing interventions that use an intersectional analysis and that impact multiple systems,
   - centering Blackness and building community, cultural, economic, and political power of Black, Indigenous, and other People of Color (BIPOC), and
   - applying the practice of love along with disruption and resistance to the status quo.

   Source:

   1. Race Forward. Race Reporting Guide. 2015. Available online: https://www.raceforward.org/reporting-guide.
   2. Maggie Potapchuk, "Operationalizing Racial Justice in Non-Profit Organizations" (MP Associates, 2020). This definition is based on and expanded from the one described in Rinku Sen and Lori Villarosa, "Grantmaking with a Racial Justice Lens: A Practical Guide" (Philanthropic Initiative for Racial Equity, 2019).

Definitions as applied to grantmaking:

RACIAL EQUITY

- PRE (Philanthropic Initiative for Racial Equity) and Candid adopted a broad definition of racial equity funding to capture the full range of grantmaking in this space. "We define funding for racial equity as grantmaking explicitly awarded to benefit people of color broadly or to organizations that explicitly serve these populations. This grantmaking specifies a focus on people of color but may focus on any number of issues (e.g., arts, education, health) or use any number of approaches (e.g., service delivery, research, advocacy.) "
- A grant may be intended to benefit communities of color, but if the funder hasn't made that dimension explicit in the grant description or the recipient organization doesn't specify a focus on racial/ethnic groups in its mission, Candid won't be able to capture it as such. Candid's approach to coding doesn't assume, for example, that a job training program in an area where the majority of the population are people of color actually supports people of color without that information having been made explicit.

RACIAL JUSTICE

- According to PRE, compared with racial equity funding, grantmaking with a racial justice lens "evokes a higher standard" and "[brings] into view the confrontation of power, the redistribution of resources, and the systemic transformation necessary for real change." Candid defines racial justice funding as that awarded to address the underlying systems and structures that generate and reinforce racial inequality. This funding is awarded to programs or organizations focused on changing systems, often through movement building, policy work, and other rights-based approaches.
- Candid's approach positions racial justice grantmaking as a subset of racial equity grantmaking. In other words, all racial justice grantmaking is also classified as racial equity, but not all racial equity grantmaking is considered to be racial justice.

Source:

1. Candid. FAQ for Candid's racial equity data. Available online: *www.candid.org/explore-issues/racial-equity/faq*

Related Resources: Philanthropic Initiative for Racial Equity. Grantmaking with a Racial Justice Lens: A Practical Guide. 2019. Available online: *www.racialequity.org/grantmaking-with-a-racial-justice-lens/*

Endnotes:

[i] HIV and American People: *https://www.cdc.gov/hiv/group/racialethnic/africanamericans/index.html*

[ii] Philanthropic Initiative for Racial Equity (PRE). Mismatched: Philanthropy's Response to the Call for Racial Justice. September 2021. Available online: https://racialequity.org/mismatched/.

[iii] FCAA. Philanthropic Support to Address HIV/AIDS in 2019. May 2021. Available online: *https://www.fcaaids.org/inform/philanthropic-support-to-address-hiv-aids/.*

HIV Organizations Announce Racial Justice Index to Remedy Disconnect Between HIV Leadership and Community Impact

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NEWS PROVIDED BY
Black AIDS Institute →
Feb 04, 2021, 08:47 ET

LOS ANGELES, Feb. 4, 2021 /PRNewswire/ -- Leading up to National Black HIV/AIDS Awareness Day, AIDS United and its Public Policy Council, composed of 55 of the nation's leading organizations dedicated to ending HIV, are announcing they have launched the *Racial Justice Index*. AIDS United is working collaboratively with the Black AIDS Institute, a Public Policy Council member, to guide this work. After the summer of 2020 that ushered in a racial reckoning in America, this novel initiative aims to create awareness — and eventually sustainable change — around the misalignment between who holds power and resources in HIV organizations and the epidemic's disproportionate impact on Black Americans.

The Racial Justice Index is part of a series of outcomes that emerged from more than two years of conversations led by leaders of color among the Public Policy Council and was made more urgent by the national outcry for racial justice. In June 2020, AIDS United, along with 53 members of its Public Policy Council and more than 20 other HIV organizations, issued an open letter to all elected officials calling for all policies to be enacted through a racial justice and equity framework. The Index's mission is to assess and improve the HIV sector's commitment to racial equity by creating assessment tools and resources to combat anti-Black racism and other forms of racism that will first be analyzed in PPC organizations and then the HIV sector. This includes hiring practices, leadership, talent retention and decision-making in the HIV movement.

The Index's methodical implementation process will seek to onboard HIV organizations to respond to an online national survey that will inform a publicly-released report, which will facilitate critical leadership conversations among HIV stakeholders.

The initiative will be guided by the Racial Justice Index Committee, a committee formed out of AIDS United's Public Policy Council and co-chaired by Raniyah Copeland, president and CEO of Black AIDS Institute, and A. Toni Young, CEO, Community Education Group — nationally renowned Black leaders in the HIV community. The PPC and the Index committee are managed by Carl Baloney Jr., AIDS United vice president for policy and advocacy. AIDS United Board members, Dr. Kimberley Jeffries Leonard, president of Links Inc., and Dr. David Holtgrave, Dean of the University at Albany School of Public Health, SUNY, have also been instrumental in assisting in the creation of the Index. The committee includes HIV service and advocacy organizations from across the country. The work of the Racial Justice Index will first assess how leadership in the HIV movement reflects the communities most impacted and will later aim to provide training and capacity building to root out white supremacy in HIV organizations' work.

"As a Black man living with HIV, I am very proud of our diverse coalition of organizations making this commitment to racial justice. Since the start of the HIV epidemic, AIDS United has played an active role to ensure that all who are living with and vulnerable to HIV receive the care they need. We are in a moment where the HIV sector — and the health care sector as a whole — must look inward and ask ourselves if our structures and decisions truly reflect the people and needs of those most impacted by the epidemic. The Public Policy Council has always pushed for responsiveness and inclusiveness across the HIV sector. This carries that work forward in these pressing times when health inequities are at our nation's forefront. We cannot end HIV without ending the systemic racism that is too often embedded in processes that result in the disparities in new infections and lack of access to care. I know it is time for change, and we are eager to put in the required work to end racist inequities and the imprint of systemic racism in our sector." — **Jesse Milan Jr., President and CEO, AIDS United**

"For 21 years, the Black AIDS Institute has led the fight to end HIV from a uniquely and unapologetically Black lens. With Black Empowerment as a central value, our leadership and our staff represent the communities we serve. By partnering with AIDS United and drawing from the intersectional expertise of the 55 Public Policy Council organizations, the *Racial Justice Index* will catalyze the prioritization of Black leadership, resource allocation, and capacity building. If we are committed to ending HIV within our lifetimes, rectifying the stain of white supremacy in how we do our work must be of the utmost priority." **— Raniyah Copeland, President and CEO, Black AIDS Institute, co-chair of AIDS United's Racial Justice Index Committee**

"HIV, HCV and Substance Use Disorder rage through Black and poor rural communities across the United States, it is critical the organizations are equipped to address the needs or Black people in the rural and Southern communities. The Racial Index will provide a tool for organizations to better develop staff and meet the growing needs of Black and brown communities." **— A. Toni Young, Founder and Executive Director, Community Education Group, co-chair of AIDS United's Racial Justice Index Committee**

"We are proud of the AIDS United Public Policy Council for deepening our commitment to racial justice through the important and urgent work to create the racial justice index. This initiative will help us examine the HIV sector's commitment to racial equity and empower us all with the resources needed to end the HIV epidemic, starting with our own organizations."
— AIDS United Public Policy Council Co-Chairs Bill Keeton, Vivent Health vice president and chief advocacy officer, and Dr. Tyler TerMeer, Cascade AIDS Project chief executive officer

"On National Black HIV/AIDS Awareness Day, I join AIDS United's Public Policy Council to celebrate the launch of the Racial Justice Index, an initiative designed for HIV service organizations to conduct internal reviews aimed at eliminating racist structures, policies, and hiring practices within them. The HIV/AIDS epidemic's disproportionate impact on Black Americans is rooted in systemic racism and the Racial Justice Index provides a tool for HIV organizations to reassess their internal structures. The Racial Justice Index is a much needed mechanism to center racial equity at the core of the HIV sector's commitment to ending the HIV epidemic." **— Congresswoman Barbara Lee, Co-Chair of the Congressional HIV/AIDS Caucus**

"I applaud AIDS United for launching the *Racial Justice Index* on National Black HIV/AIDS Awareness Day. The HIV/AIDS pandemic has had a devastating impact upon African Americans and other communities of color. In order for AIDS service and advocacy organizations to effectively address these devastating disparities, they must accurately reflect the demographics of the people who need their services."
— Congresswoman Maxine Waters

ABOUT AIDS UNITED

AIDS United's mission is to end the HIV epidemic in the U.S. through strategic grant-making, capacity building and policy. AIDS United works to ensure access to life-saving HIV care and prevention services and to advance sound HIV-related policy for populations and communities most impacted by the U.S. epidemic. To date, AIDS United's strategic grant-making initiatives have directly funded more than $104 million to local communities and have leveraged more than $117 million in additional investments for programs that include, but are not limited to, HIV prevention, access to care, capacity building, harm reduction and advocacy. Learn more at www.aidsunited.org

ABOUT BLACK AIDS INSTITUTE

Founded in 1999, Black AIDS Institute (BAI) is the only uniquely and unapologetically Black *think and do tank* in America. Our mission is "to stop the AIDS epidemic in Black communities by engaging and mobilizing Black institutions and individuals to confront HIV." Black Empowerment is our central theme and we are led by people who represent the issues we serve. We source our capacity building, mobilization, and advocacy efforts from Black leaders and communities across the country, and provide culturally respectful, high-quality, HIV prevention and care services for Black people in Los Angeles. Learn more at https://blackaids.org

ABOUT AIDS UNITED PUBLIC POLICY COUNCIL

AIDS United's Public Policy Council is the nation's largest and longest-running policy coalition of community-based HIV organizations. Supported by the AIDS United Policy Department, the Public Policy Council brings together organizations from across the United States to advocate for people living with or impacted by HIV/AIDS and the organizations that serve them. The Public Policy Council operates as a standing committee of the AIDS United Board of Trustees, informing the policy priorities of the organization. Learn more at www.aidsunited.org

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NEWSFEED (/CATEGORY/NEWSFEED)

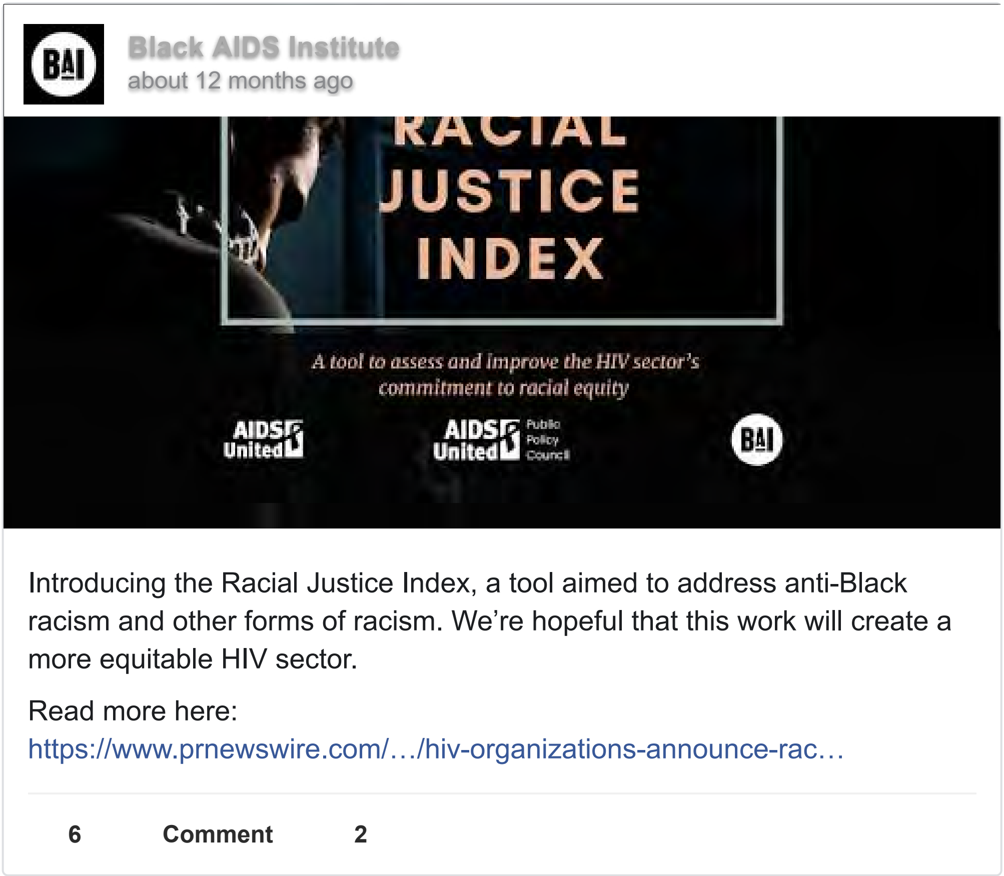
Racial Justice Index: A New Tool to Combat Racism Within HIV Groups

Guided by AIDS United and the Black AIDS Institute, the index aims to assess and improve racial equity in the HIV sector.

February 5, 2021 By Trenton Straube (/author/trenton-straube)

A coalition of AIDS leaders has launched the Racial Justice Index, an initiative to combat racism within the HIV movement and to assess and improve racial equity within HIV organizations that provide advocacy and health services. For example, the index can help identify and address systemic racism and disparities in a group's hiring practices, decision-making processes and internal structures.

Or, as a press release from Black AIDS Institute (https://www.prnewswire.com/news-releases/hiv-organizations-announce-racial-justice-index-to-remedy-disconnect-between-hiv-leadership-and-community-impact-301222224.html) explains it: “This novel initiative aims to create awareness—and eventually sustainable change—around the misalignment between who holds power and resources in HIV organizations and the epidemic’s disproportionate impact on Black Americans.”



Introducing the Racial Justice Index, a tool aimed to address anti-Black racism and other forms of racism. We’re hopeful that this work will create a more equitable HIV sector.

Read more here:
https://www.prnewswire.com/…/hiv-organizations-announce-rac…

The Racial Justice Index is the collaborative effort of advocacy group AIDS United and its Public Policy Council, which includes 55 HIV organizations across the nation. The Black AIDS Coalition will help spearhead the effort. The index’s launch coincides with the upcoming National Black HIV/AIDS Awareness Day (#NBHAAD) (https://www.poz.com/article/national-black-hivaids-awareness-day-2021), marked each February 7, which is this Sunday.

The first goal of the index is to analyze whether leadership within the HIV movement reflects the communities it serves. This will be assessed through online national surveys crafted to also spark vital discussions in the HIV community. The index, according to the press release, also plans to offer training on how to "root out white supremacy in HIV organizations' work" while helping the groups build their strengths, output and sustainability.

"The Racial Justice Index will catalyze the prioritization of Black leadership, resource allocation and capacity building," said Raniyah Copeland, president of the Black AIDS Institute and cochair of AIDS United's Racial Justice Index committee. "If we are committed to ending HIV within our lifetimes, rectifying the stain of white supremacy in how we do our work must be of the utmost priority."

"HIV, [hepatitis C] and substance use disorder rage through Black and poor rural communities across the United States," added A. Toni Young, CEO of the Community Education Group and another member of the index's committee. "It is critical the organizations are equipped to address the needs of Black people in the rural and Southern communities. The Racial Index will provide a tool for organizations to better develop staff and meet the growing needs of Black and brown communities."

Congresswoman Barbara Lee (D–California), cochair of the Congressional HIV/AIDS Caucus, also praised the new initiative. "The HIV/AIDS epidemic's disproportionate impact on Black Americans is rooted in systemic racism," she stated in the press release. "The Racial Justice Index provides a tool for HIV organizations to reassess their internal structures. The Racial Justice Index is a much-needed mechanism to center racial equity at the core of the HIV sector's commitment to ending the HIV epidemic."

Read the complete press release for further details and insights and quotes from HIV leaders. In related news, for a recent POZ profile on Raniyah Copeland, see “Black Voices Matter (https://www.poz.com/article/black-voices-matter-raniyah-copeland).” And don’t miss AIDS United’s policy blog (https://www.poz.com/blogger/aids-united) on POZ.com, which includes regular assessments of HIV issues relating to Congress and the White House.

For related POZ articles, see “Behind the Partnership to Transform Black and Brown HIV Efforts (https://www.poz.com/article/behind-new-32m-partnership-hrc-gilead-sciences-transform-black-latino-transgender-hiv-efforts)” and “The Most Important Health Concerns of Black LGBTQ Americans (https://www.poz.com/article/important-health-concerns-black-lgbtq-americans).” Finally, you can learn more about HIV among African Americans (https://www.poz.com/basics/hiv-basics/hiv-african-americans)—and several other minority populations—by visiting the HIV/AIDS Basics on POZ.com (https://www.poz.com/basics/hiv-basics) and clicking on the “HIV in Specific Populations” section.

NATIONAL HIV/AIDS STRATEGY

for the United States 2022–2025

THE WHITE HOUSE
WASHINGTON

Acknowledgments: The National HIV/AIDS Strategy (NHAS or Strategy) was developed by the White House Office of National AIDS Policy (ONAP) in collaboration with federal partners and with input from the HIV community across the country. Interested parties and organizations throughout the federal government and those engaged in work in many different communities have helped shape the goals, objectives, and strategies in the Strategy. ONAP extends the gratitude and appreciation of the White House to everyone who made thoughtful recommendations and recommitted to the Strategy's vision and goals. ONAP also offers thanks to the team at the Office of Infectious Disease and HIV/AIDS Policy in the U.S. Department of Health and Human Services for its many contributions to developing the Strategy.

Language used in the National HIV/AIDS Strategy: The Strategy honors the lived experiences and choices of all people, regardless of age, sex, gender identity, sexual orientation, race, ethnicity, religion, disability, geographic location, or socioeconomic circumstance. To reflect this, authors made a concerted effort to use inclusive and person-first language throughout the strategy. Evidence-based, contemporary terminology is also used to convey respect and to reduce stigma faced by communities and populations disproportionately impacted by HIV. This approach is intended to reflect the administration's vision for a collective, inclusive, and respectful national response. Despite these efforts, in certain instances, for example to accurately convey scientific meaning, specific terminology or language may be unintentionally offensive or stigmatizing to some individuals or populations.

Additional information regarding the Strategy and associated activities may be accessed at the White House website.

Suggested citation: The White House. 2021. *National HIV/AIDS Strategy for the United States 2022–2025.* Washington, DC.

The National HIV/AIDS Strategy is not a budget document and does not imply approval for any specific action under Executive Order 12866 or the Paperwork Reduction Act. The Strategy will inform the Federal budget and regulatory development processes within the context of the goals articulated in the President's Budget. All activities included in the Strategy are subject to budgetary constraints and other approvals, including the weighing of priorities and available resources by the Administration in formulating its annual budget and by Congress in legislating appropriations.

VISION

The United States will be a place where new HIV infections are prevented, every person knows their status, and every person with HIV has high-quality care and treatment, lives free from stigma and discrimination, and can achieve their full potential for health and well-being across the lifespan.

This vision includes all people, regardless of age, sex, gender identity, sexual orientation, race, ethnicity, religion, disability, geographic location, or socioeconomic circumstance.

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EXECUTIVE SUMMARY

Building on lessons learned and progress made in the past 40 years, the United States now has the opportunity to end the HIV epidemic. This opportunity has been made possible by tireless advocacy, determined research, and dedicated delivery of diagnostic, prevention, care, treatment, and supportive services.

The nation's annual new HIV infections have declined from their peak in the mid-1980s, and people with HIV in care and treatment are living longer, healthier lives. In 2019, the estimated number of new HIV infections was 34,800 and 1.2 million people were living with HIV in the United States. However, not all groups have experienced decreases in HIV infections or improvements in health outcomes. Centers for Disease Control and Prevention data show that new HIV infections fell 8% from 2015 to 2019, after a period of general stability in new infections in the United States. This trend represents a hopeful sign of progress. But gains remain uneven, illuminating opportunities for geographic- and population-focused efforts to make more effective use of the powerful HIV prevention, care, and treatment tools now available.

This National HIV/AIDS Strategy (the Strategy), the nation's third national HIV strategy, updates the HIV National Strategic Plan (2021). The Strategy sets forth bold targets for ending the HIV epidemic in the United States by 2030, including a 75% reduction in new HIV infections by 2025 and a 90% reduction by 2030. For interested parties and organizations across the nation, the Strategy articulates goals, objectives, and strategies to prevent new infections, treat people with HIV to improve health outcomes, reduce HIV-related disparities, and better integrate and coordinate the efforts of all partners to achieve the bold targets for ending the epidemic. The Strategy also establishes evidence-based indicators to measure progress, with quantitative targets for each indicator, and designates priority populations.

The Strategy establishes the following vision:

The United States will be a place where new HIV infections are prevented, every person knows their status, and every person with HIV has high-quality care and treatment, lives free from stigma and discrimination, and can achieve their full potential for health and well-being across the lifespan.

This vision includes all people, regardless of age, sex, gender identity, sexual orientation, race, ethnicity, religion, disability, geographic location, or socioeconomic circumstance.

The vision, goals, objectives, and other components of the Strategy were developed and approved by a dedicated Steering Committee, composed of subject matter experts from across the federal government, with input from numerous and varied interested parties and organizations in the field. The Strategy is designed to be accessible to and useful for a broad audience, including people working in public health, health care, government, community-based organizations, research, private industry, and academia. It serves as a roadmap for all sectors of society to guide development of policies, services, programs, initiatives, and other actions to achieve the nation's goal of ending the HIV epidemic by 2030.

The Strategy is designed to facilitate a whole-of-society national response to the HIV epidemic in the United States that accelerates efforts to end the HIV epidemic in the United States by 2030 while supporting people with HIV and reducing HIV-associated morbidity and mortality. While not every objective or strategy will speak to or be actionable by all readers, the intent is that individuals and organizations from all sectors of society can find opportunities where they can support necessary scale-up, expansion, and refinement efforts. All communities, regardless of HIV prevalence, are vital to ending the HIV epidemic in this country and private- and public-sector partners must work together with community-based, faith-focused, and advocacy organizations; governmental public health; mental health and substance use disorder treatment services; the criminal justice system; and providers of housing, food and nutrition, education, and employment services because we all have a role in reducing new HIV infections, improving outcomes and quality of life for people with HIV, and eliminating HIV disparities.

Interwoven throughout the Strategy are approaches to address the individual, community, and structural factors and inequities that contribute to the spread of HIV, such as stigma and social determinants of health. The Strategy highlights opportunities to integrate HIV prevention, care, and treatment into prevention and treatment for sexually transmitted infections, viral hepatitis, mental health and substance use disorders, and other public health efforts by leveraging capacity and infrastructure across the domains and breaking down operational and funding silos. A recurring theme is the need to bring to scale innovative solutions and data-driven approaches to address the ongoing and emerging challenges to HIV prevention, care, and treatment, including expanding the types of community and clinical sites that address HIV to help reach and engage people in need of services; supporting retention in HIV prevention and care services; continuing research into development of better prevention tools, therapeutics, and vaccines; and understanding how to make best use of available tools in real-world settings. Throughout this document, the term “care” is used as an umbrella term meant to encompass holistic services including treatment and supportive services.

To ensure implementation and accountability, a Federal Implementation Plan that documents the specific actions that federal partners will take to achieve the Strategy’s goals and objectives will be developed in early 2022. Progress toward meeting the Strategy’s goals will be monitored and reported annually.

The Strategy and the *Ending the HIV Epidemic in the U.S.* (EHE) initiative are closely aligned and complementary, with EHE serving as a leading component of the work by the U.S. Department of Health and Human Services (HHS), in collaboration with local, state, tribal, federal, and community partners, to achieve the Strategy’s goals. The EHE initiative focuses on scaling up four strategies in the communities most affected by HIV. The Strategy covers the entire country, has a broader focus across federal departments and agencies beyond HHS and all sectors of society, and addresses the integration of several key components that are vital to our collective work, including stigma, discrimination, and social determinants of health.

NHAS AT-A-GLANCE

This At-A-Glance section briefly summarizes the Goals, Objectives, and Strategies that are discussed in detail in the narrative that follows.

Goal 1: Prevent New HIV Infections

1.1 Increase awareness of HIV

1.1.1 Develop and implement campaigns, interventions, and resources to provide education about comprehensive sexual health; HIV risks; options for prevention, testing, care, and treatment; and HIV-related stigma reduction.

1.1.2 Increase knowledge of HIV among people, communities, and the health workforce in geographic areas disproportionately affected.

1.1.3 Integrate HIV messaging into existing campaigns and other activities pertaining to other parts of the syndemic, such as STIs, viral hepatitis, and substance use and mental health disorders, as well as in primary care and general wellness, and as part of annual reproductive health visits and wellness visits.

1.2 Increase knowledge of HIV status

1.2.1 Test all people for HIV according to the most current USPSTF recommendations and CDC guidelines.

1.2.2 Develop new and expand implementation of effective, evidence-based, or evidence-informed models for HIV testing that improve convenience and access.

1.2.3 Incorporate a status-neutral approach to HIV testing, offering linkage to prevention services for people who test negative and immediate linkage to HIV care and treatment for those who test positive.

1.2.4 Provide partner services to people diagnosed with HIV or other STIs and their sexual and/or syringe-sharing partners.

1.3 Expand and improve implementation of safe, effective prevention interventions, including treatment as prevention, PrEP, PEP, and SSPs, and develop new options

1.3.1 Engage people who experience risk for HIV in traditional public health and health care delivery systems, as well as in nontraditional community settings.

1.3.2 Scale up treatment as prevention (i.e., U=U) by diagnosing all people with HIV, as early as possible, and engaging them in care and treatment to achieve and maintain viral suppression.

1.3.3 Make HIV prevention services, including condoms, PrEP, PEP, and SSPs, easier to access and support continued use.

1.3.4 Implement culturally competent and linguistically appropriate models and other innovative approaches for delivering HIV prevention services.

1.3.5 Support research into the development and evaluation of new HIV prevention modalities and interventions for preventing HIV transmissions in priority populations.

1.3.6 Expand implementation research to successfully adapt evidence-based interventions to local environments to maximize potential for uptake and sustainability.

1.4 Increase the diversity and capacity of health care delivery systems, community health, public health, and the health workforce to prevent and diagnose HIV

1.4.1 Provide resources, incentives, training, and technical assistance to expand workforce and systems capacity to provide or link clients to culturally competent, linguistically appropriate, and accessible HIV testing, prevention, and supportive services especially in areas with shortages that are geographic, population, or facility based.

1.4.2 Increase the diversity of the workforce of providers who deliver HIV prevention, testing, and supportive services.

1.4.3 Increase the inclusion of paraprofessionals on prevention teams by advancing training, certification, supervision, financing, and team-based care service delivery.

1.4.4 Include comprehensive sexual health and substance use prevention and treatment information in curricula of medical and other health workforce education and training programs.

Goal 2: Improve HIV-Related Health Outcomes of People with HIV

2.1 Link people to care immediately after diagnosis and provide low-barrier access to HIV treatment

2.1.1 Provide same-day or rapid (within 7 days) start of antiretroviral therapy for persons who are able to take it; increase linkage to HIV health care within 30 days for all persons who test positive for HIV.

2.1.2 Increase the number of schools providing on-site sexual health services through school-based health centers and school nurses, and linkages to HIV testing and medical care through youth-friendly providers in the community.

2.2 Identify, engage, or reengage people with HIV who are not in care or not virally suppressed

2.2.1 Expand uptake of data-to-care models using data sharing agreements, integration and use of surveillance, clinical services, pharmacy, and social/support services data to identify and engage people not in care or not virally suppressed.

2.2.2 Identify and address barriers for people who have never engaged in care or who have fallen out of care.

2.3 Increase retention in care and adherence to HIV treatment to achieve and maintain long-term viral suppression and provide integrative HIV services for HIV-associated comorbidities, coinfections, and complications, including STIs

2.3.1 Support the transition of health care systems, organizations, and patients/clients to become more health literate in the provision of HIV prevention, care, and treatment services.

2.3.2 Develop and implement effective, evidence-based, or evidence-informed interventions and supportive services that improve retention in care.

2.3.3 Expand implementation research to successfully adapt effective evidence-based interventions, such as HIV telehealth, patient and peer navigators, accessible pharmacy services, community health workers, and others, to local environments to facilitate uptake and retention to priority populations.

2.3.4 Support ongoing clinical, behavioral, and other research to support retention in care, medication adherence, and durable viral suppression.

2.4 Increase the capacity of the public health, health care delivery systems, and health care workforce to effectively identify, diagnose, and provide holistic care and treatment for people with HIV

2.4.1 Provide resources, value-based and other incentives, training, and technical assistance to expand workforce and systems capacity to provide or link clients to culturally competent and linguistically appropriate care, treatment, and supportive services especially in areas with shortages that are geographic, population, or facility based.

2.4.2 Increase the diversity of the workforce of providers who deliver HIV care and supportive services.

2.4.3 Increase inclusion of paraprofessionals on teams by advancing training, certification, supervision, reimbursement, and team functioning to assist with screening/management of HIV, STIs, viral hepatitis, and mental and substance use disorders and other behavioral health conditions.

2.5 Expand capacity to provide whole-person care to older adults with HIV and long-term survivors

2.5.1 Identify, implement, and evaluate models of care that meet the needs of people with HIV who are aging and ensure quality of care across services.

2.5.2 Identify and implement best practices related to addressing psychosocial and behavioral health needs of older people with HIV and long-term survivors including substance use treatment, mental health treatment, and programs designed to decrease social isolation.

2.5.3 Increase HIV awareness, capability, and collaboration of service providers to support older people with HIV, including in settings such as aging services, housing for older adults, substance use treatment, and disability and other medical services.

2.5.4 Promote research, cross-agency collaborations, and sharing of research discoveries that address specific aging-related conditions in people with HIV, and other comorbidities and coinfections that can impact people with HIV of all ages.

2.5.5 Develop and optimize collaborative multi-agency and multi-sectoral approaches and strategies to address emergent and evolving challenges facing people living with HIV at various life stages to support healthy aging with HIV.

2.6 Advance the development of next-generation HIV therapies and accelerate research for HIV cure

2.6.1 Promote research and encourage public-private partnerships to accelerate new therapies to achieve sustained viral suppression and to address drug toxicity, viral resistance, adherence, and retention in care and stigma associated with ART use.

2.6.2 Increase investment in innovative basic and clinical research to inform and accelerate a research agenda to discover how to sustain viral suppression, achieve ART-free remission, reduce and eliminate viral reservoirs, and achieve HIV cure.

Goal 3: Reduce HIV-Related Disparities and Health Inequities

3.1 Reduce HIV-related stigma and discrimination

3.1.1 Strengthen enforcement of civil rights laws (including language access services and disability rights), promote reform of state HIV criminalization laws, and assist states in protecting people with HIV from violence, retaliation, and discrimination associated with HIV status, homophobia, transphobia, xenophobia, racism, substance use, and sexism.

3.1.2 Ensure that health care professionals and front-line staff complete education and training on stigma, discrimination, and unrecognized bias toward populations with or who experience risk for HIV, including LGBTQI+ people, immigrants, people who use drugs, and people involved in sex work.

3.1.3 Support communities in efforts to address misconceptions and reduce HIV-related stigma and other stigmas that negatively affect HIV outcomes.

3.1.4 Ensure resources are focused on the communities and populations where the need is greatest, especially Black, Latino, and American Indian/Alaska Native and other people of color, particularly those who are also gay and bisexual men, transgender people, people who use substances, sex workers, and immigrants.

3.1.5 Create funding opportunities that specifically address social and structural drivers of health as they relate to Black, Latino, and American Indian/Alaska Native and other people of color.

3.2 Reduce disparities in new HIV infections, in knowledge of status, and along the HIV care continuum

3.2.1 Increase awareness of HIV-related disparities through data collection, analysis, and dissemination of findings.

3.2.2 Develop new and scale up effective, evidence-based or evidence-informed interventions to improve health outcomes among priority populations and other populations or geographic areas experiencing disparities.

3.3 Engage, employ, and provide public leadership opportunities at all levels for people with or who experience risk for HIV

3.3.1 Create and promote public leadership opportunities for people with or who experience risk for HIV.

3.3.2 Work with communities to reframe HIV services and HIV-related messaging so that they do not stigmatize people or behaviors.

3.4 Address social and structural determinants of health and co-occurring conditions that impede access to HIV services and exacerbate HIV-related disparities

3.4.1 Develop whole-person systems of care and wellness that address co-occurring conditions for people with or who experience risk for HIV.

3.4.2 Adopt policies that reduce cost, payment, coverage, and/or access barriers to improve the delivery and receipt of services for people with or who experience risk for HIV.

3.4.3 Improve screening and linkage to services for people with or who experience risk for HIV who are diagnosed with and/or are receiving services for co-occurring conditions.

3.4.4 Develop and implement effective, evidence-based and evidence-informed interventions that address social and structural determinants of health among people with or who experience risk for HIV including lack of continuous health care coverage, HIV-related stigma and discrimination in public health and health care systems, medical mistrust, inadequate housing and transportation, food insecurity, unemployment, low health literacy, and involvement with the justice system.

3.4.5 Increase the number of schools that have implemented LGBTQ-supportive policies and practices, including (1) having a Gay/Straight Alliance (GSA), Gender Sexuality Alliance, or similar clubs, (2) identifying safe spaces, (3) adopting policies expressly prohibiting discrimination and harassment based on sexual orientation or gender identity, (4) encouraging staff to attend professional development, (5) facilitating access to out-of-school health service providers, (6) facilitating access to out-of-school social and psychological service providers, and (7) providing LGBTQ-relevant curricula or supplementary materials.

3.4.6 Develop new and scale up effective, evidence-based or evidence-informed interventions that address intersecting factors of HIV, homelessness or housing instability, mental health and violence, substance use, and gender especially among cis- and transgender women and gay and bisexual men.

3.5 Train and expand a diverse HIV workforce by further developing and promoting opportunities to support the next generation of HIV providers including health care workers, researchers, and community partners, particularly from underrepresented populations

3.5.1 Promote the expansion of existing programs and initiatives designed to increase the numbers of non-White research and health professionals.

3.5.2 Increase support for the implementation of mentoring programs for individuals from diverse cultural backgrounds to expand the pool of HIV research and health professionals.

3.5.3 Encourage the implementation of effective recruitment of community partners through community-based participatory research and social networking approaches.

3.6 Advance HIV-related communications to achieve improved messaging and uptake, as well as to address misinformation and health care mistrust

3.6.1 Develop and test strategies to promote accurate creation, dissemination, and uptake of information and to counter associated misinformation and disinformation.

3.6.2 Increase diversity and cultural competence in health communication research, training, and policy.

3.6.3 Expand community engagement in health communication initiatives and research.

3.6.4 Include critical analysis and health communication skills in HIV programs to provide participants with the tools to seek and identify accurate health information and to advocate for themselves and their communities.

3.6.5 Expand effective communication strategies between providers and consumers to build trust, optimize collaborative decision-making, and promote success of evidence-based prevention and treatment strategies.

Goal 4: Achieve Integrated, Coordinated Efforts That Address the HIV Epidemic among All Partners and Interested Parties

4.1 Integrate programs to address the syndemic of HIV, STIs, viral hepatitis, and substance use and mental health disorders in the context of social and structural/institutional factors including stigma, discrimination, and violence

4.1.1 Integrate HIV awareness and services into outreach and services for issues that intersect with HIV such as intimate partner violence, homelessness or housing instability, STIs, viral hepatitis, and substance use and mental health disorders.

4.1.2 Implement a no-wrong-door approach to screening and linkage to services for HIV, STIs, viral hepatitis, and substance use and mental health disorders across programs.

4.1.3 Identify and address funding, policy, data, workforce capacity, and programmatic barriers to effectively address the syndemic.

4.1.4 Coordinate and align strategic planning efforts on HIV, STIs, viral hepatitis, substance use disorders, and mental health care across national, state, and local partners.

4.1.5 Enhance the ability of the HIV workforce to provide naloxone and educate people on the existence of fentanyl in the drug supply to prevent overdose and deaths and facilitate linkage to substance use disorder treatment and harm reduction programs.

4.2 Increase coordination among and sharing of best practices from HIV programs across all levels of government (federal, state, tribal, local, and territorial) and with public and private health care payers, faith-based and community-based organizations, the private sector, academic partners, and the community

4.2.1 Focus resources including evidence-based and evidence-informed interventions in the geographic areas and priority populations disproportionately affected by HIV.

4.2.2 Enhance collaboration among local, state, tribal, territorial, national, and federal partners and the community to address policy and structural barriers that contribute to persistent HIV-related disparities and implement policies that foster improved health outcomes.

4.2.3 Coordinate across partners to quickly detect and respond to HIV outbreaks.

4.2.4 Support collaborations between community-based organizations, public health organizations, education agencies and schools, housing providers, and health care delivery systems to provide linkage to and delivery of HIV testing, prevention, care, and treatment services as well as supportive services.

4.3 Enhance the quality, accessibility, sharing, and uses of data, including HIV prevention and care continua data and social determinants of health data

4.3.1 Promote the collection, electronic sharing, and use of HIV risk, prevention, and care and treatment data using interoperable data standards, including data from electronic health records, in accordance with applicable law.

4.3.2 Use interoperable health information technology, including application programming interfaces (APIs), clinical decision support tools, electronic health records and health IT products certified by the Office of the National Coordinator's Health IT Certification Program, and health information exchange networks, to improve HIV prevention efforts and care outcomes.

4.3.3 Encourage and support patient access to and use of their individual health information, including use of their patient-generated health information and use of consumer health technologies in a secure and privacy supportive manner.

4.4 Foster private-public-community partnerships to identify and scale up best practices and accelerate HIV advances

4.4.1 Adopt approaches that incentivize the scale up of effective interventions among academic centers, health departments, community-based organizations, allied health professionals, people with HIV and their advocates, the private sector, and other partners.

4.4.2 Expand opportunities and mechanisms for information sharing and peer technical assistance within and across jurisdictions to move effective interventions into practice more swiftly.

4.4.3 Develop and optimize collaborative multi-agency and multi-sectoral approaches and strategies to address emergent and evolving challenges facing persons of all ages living with HIV.

4.5 Improve mechanisms to measure, monitor, evaluate, and use the information to report progress and course correct as needed in order to achieve the Strategy's goals

4.5.1 Streamline and harmonize reporting and data systems to reduce burden and improve the timeliness, availability, and usefulness of data.

4.5.2 Monitor, review, evaluate, and regularly communicate progress on the National HIV/AIDS Strategy.

4.5.3 Ensure that the National HIV/AIDS Strategy's goals and priorities are included in cross-sector federal funding requirements.

4.5.4 Strengthen monitoring and accountability for adherence to requirements, targets, and goals by funded partners.

4.5.5 Identify and address barriers and challenges that hinder achievement of goals by funded partners and other interested parties.

INDICATORS AT-A-GLANCE

Indicator 1: Increase knowledge of status to 95% from a 2017 baseline of 85.8%.

Indicator 2: Reduce new HIV infections by 75% from a 2017 baseline of 37,000.

Indicator 3: Reduce new HIV diagnoses by 75% from a 2017 baseline of 38,351.

Indicator 4: Increase PrEP coverage to 50% from a 2017 baseline of 13.2%.

Indicator 5: Increase linkage to care within 1 month of diagnosis to 95% from a 2017 baseline of 77.8%.

Indicator 6: Increase viral suppression among people with diagnosed HIV to 95% from a 2017 baseline of 63.1%.

> **Indicator 6a:** Increase viral suppression among MSM diagnosed with HIV to 95% from a 2017 baseline of 66.1%.
>
> **Indicator 6b:** Increase viral suppression among Black MSM diagnosed with HIV to 95% from a 2017 baseline of 58.4%.
>
> **Indicator 6c:** Increase viral suppression among Latino MSM diagnosed with HIV to 95% from a 2017 baseline of 64.9%.
>
> **Indicator 6d:** Increase viral suppression among American Indian/Alaska Native MSM diagnosed with HIV to 95% from a 2017 baseline of 67.3%.
>
> **Indicator 6e:** Increase viral suppression among Black women diagnosed with HIV to 95% from a 2017 baseline of 59.3%.
>
> **Indicator 6f:** Increase viral suppression among transgender women in HIV medical care to 95% from a 2017 baseline of 80.5%.
>
> **Indicator 6g:** Increase viral suppression among people who inject drugs diagnosed with HIV to 95% from a 2017 baseline of 54.9%.
>
> **Indicator 6h:** Increase viral suppression among youth aged 13-24 diagnosed with HIV to 95% from a 2017 baseline of 57.1%.

Indicator 7: Decrease stigma among people with diagnosed HIV by 50% from a 2018 baseline median score of 31.2 on a 10-item questionnaire.

Indicator 8: Reduce homelessness among people with diagnosed HIV by 50% from a 2017 baseline of 9.1%.

Indicator 9: Increase the median percentage of secondary schools that implement at least 4 out of 7 LGBTQ-supportive policies and practices to 65% from a 2018 baseline of 59.8%.

In addition, quality of life for people with HIV was designated as the subject for a developmental indicator, meaning that data sources, measures, and targets will be identified and progress monitored thereafter.

INTRODUCTION

HIV EPIDEMIC: PROGRESS TO DATE

After nearly 40 years of tireless advocacy, determined research, and dedicated delivery of diagnostic, prevention, care, treatment, and supportive services, the United States now has the opportunity to end the HIV epidemic. Since it was first discovered in 1981, HIV has affected the lives of millions of people across the nation. Today, through the ongoing commitment of interested parties and organizations from many sectors, as well as landmark biomedical and scientific research advances, the nation has many effective HIV diagnostics, prevention strategies, and improved care and treatment models. New laboratory and epidemiological approaches enable us to identify where HIV is spreading most rapidly and to respond swiftly to stop the further spread of new HIV transmissions.

Over the past decade, the HIV response in the United States has been guided by the National HIV/AIDS Strategy (NHAS or Strategy), first released in 2010 and updated in 2015. The Strategy has changed the way that Americans talk about HIV, prioritize and coordinate resources, and deliver prevention and care services along with other clinical and nonclinical services that support people with or who experience risk for HIV. It has also led to increased collaboration among federal agencies; people with or who experience risk for HIV; state, local, tribal, and territorial governments; health care providers; researchers; faith communities; and many other community partners. Since the release of those first national strategies, several important achievements have bolstered the nation's HIV response:

- **Population-level viral suppression has increased.** After the NHAS was released, the Centers for Disease Control and Prevention (CDC) published its first national estimates of the share of all people with HIV who have achieved viral suppression, finding that only about one in four people with HIV (27.9%) in the United States was virally suppressed in 2010.[1] By 2019, however, viral suppression rates in the United States had doubled to 57%.[2] Although still too low, these rates represent real progress.
- **HIV diagnoses have declined, especially in key groups.** HIV diagnosis rates were relatively stable for many years prior to the release of the NHAS. CDC data suggest that annual new diagnoses declined by 14.3% from 2010 (42,938) when the Strategy was released to 2019 (36,337).[3, 4] Large declines occurred in some groups, including women. Deaths declined by 7.6% from 2010 (16,726) to 2019 (15,463).[3, 4]
- **Outcome disparities within the Ryan White HIV/AIDS Program have decreased.** Nearly 9 in 10 clients of the Health Resources and Services Administration's (HRSA's) Ryan White HIV/AIDS Program (RWHAP) were virally suppressed in 2019, and the program continues to show progress at reducing disparities across groups.[5] From 2010 to 2019, the gap between male and female clients decreased from nearly 5 percentage points to <1 percentage point. Similarly, the difference between viral suppression rates in Black clients and White clients was 13 percentage points in 2010 but 7 percentage points in 2019.[5, 6]
- **Policy changes ensure that federal money follows the epidemic.** Earlier in the epidemic, federal HIV resources to states and local governments were either allocated via a discretionary manner or via a formula that relied on cumulative AIDS cases, skewing resources toward early epicenters of the epidemic and not reflecting the current burden of HIV across the country. Prior to release of the Strategy, Congress changed the formulas used by the RWHAP to be based on living HIV/AIDS cases. The Strategy's call for federal money to follow the epidemic spurred further action. In fiscal year 2012, CDC changed the formula for its major HIV prevention program for state and local health departments to be based on living HIV/AIDS cases, and, in 2016, Congress modernized the law that authorized the Housing Opportunities for Persons With AIDS (HOPWA) program to be based on living HIV/AIDS cases.
- **The advent of pre-exposure prophylaxis (PrEP) has increased options for HIV prevention.** The first randomized controlled trial of PrEP reported results in 2010, and the U.S. Food and Drug Administration (FDA) approved the first PrEP medication in 2012. Several federal actions embraced this new biomedical

tool as an important part of comprehensive HIV prevention: for example, CDC issued interim and then final prescriber guidance; the expansion of PrEP access was a central component of the 2015 update to the NHAS; and the *Ending the HIV Epidemic in the U.S.* (EHE) initiative further sought to remove barriers to PrEP uptake, including through the establishment of the Ready, Set, PrEP program, which makes PrEP available at no cost to individuals without prescription drug coverage. Although uptake remains too low and disparities are large, the adoption of new medical technologies often takes decades, and the goal is to expedite widespread adoption of PrEP for people who can benefit from it.

- **Health insurance coverage rates for people with HIV have increased to match the general population.** In 2018, just 1 in 10 (11%) nonelderly people with HIV were uninsured, a rate on par with that of the general population (10%).[7] An estimated 42% of the adult population with HIV is covered by Medicaid, compared to 13% of the overall adult population.[8] Medicaid is the largest source of insurance coverage for people with HIV, covering a broad range of services from inpatient and outpatient care, to prescription medications, to preventive services.[9]
- **Strategic investments by the National Institutes of Health (NIH) in research have advanced efforts toward new prevention tools, next-generation therapies, a vaccine, and a cure.** NIH discovery science has been newly complemented by a suite of NIH implementation science projects designed to meet EHE initiative goals through improved use of proven HIV strategies.
- **States, cities, tribes, and local communities have developed their own HIV strategies.** These strategies (e.g., plans to end the HIV epidemic or achieve zero new infections) aligned with the NHAS and resulted in increased coordination across government agencies, nongovernmental organizations, and the private sector.
- **Interested parties and organizations have enhanced the focus on supports and support services such as housing and employment, which play key roles in enabling economic self-sufficiency and improving health outcomes.** With the effectiveness of early antiretroviral treatment (ART), many people with HIV can (and do) participate in the country's workforce. Employment is associated with improved HIV health outcomes, notably testing, linkage to care, and adherence to medication.[10] Coordination and collaboration at all levels of government and across the public and private sectors have led to an increased awareness of these supports. Moreover, the COVID-19 pandemic has led communities across the nation to employ new strategies in providing support services, improving access to food, housing, and employment services.
- **The *Ending the HIV Epidemic in the U.S.* initiative was launched in 2019.** This bold plan aims to end the HIV epidemic in the United States by 2030. EHE is the operational plan developed by agencies across the U.S. Department of Health and Human Services (HHS) to pursue that goal. The initiative leverages critical scientific advances in HIV prevention, diagnosis, treatment, and outbreak response by coordinating the highly successful programs, resources, and infrastructure of many HHS agencies and offices. The initiative is focused on areas where data show the highest numbers of new HIV infections, providing 57 geographic focus areas with a rapid infusion of additional resources, expertise, and technology to develop and implement locally tailored EHE plans.
- **President Biden issued an Executive Order on preventing and combating discrimination on the basis of gender identity or sexual orientation.** This Executive Order aims to prevent and combat discrimination on the basis of gender identity or sexual orientation, and to fully enforce Title VII and other laws that prohibit discrimination on the basis of gender identity or sexual orientation.

HIV IN THE UNITED STATES TODAY

HIV persists as a serious public health challenge in the United States. An estimated 1.2 million people in the United States had HIV at the end of 2019, the most recent year for which this information is available.[11] National HIV prevention and care efforts have taken the nation from a peak of 130,000 HIV infections annually in the mid-1980s[12] to approximately 34,800 in 2019.[10] Although HIV infection rates have decreased in the United States, new infections continue in every U.S. state with 34,800 new infections occurring in 2019.

HOPEFUL SIGNS OF PROGRESS EXIST.

The nation has seen hopeful signs of progress in recent years, but not everyone is benefiting equally from advances in HIV prevention and treatment. The latest CDC data show that new HIV infections declined by 8% from 2015 to 2019, after a period of general stability in new infections in the United States (see Figure 1). Much of this progress was due to larger declines among young gay and bisexual men in recent years.[13]

* * * * *

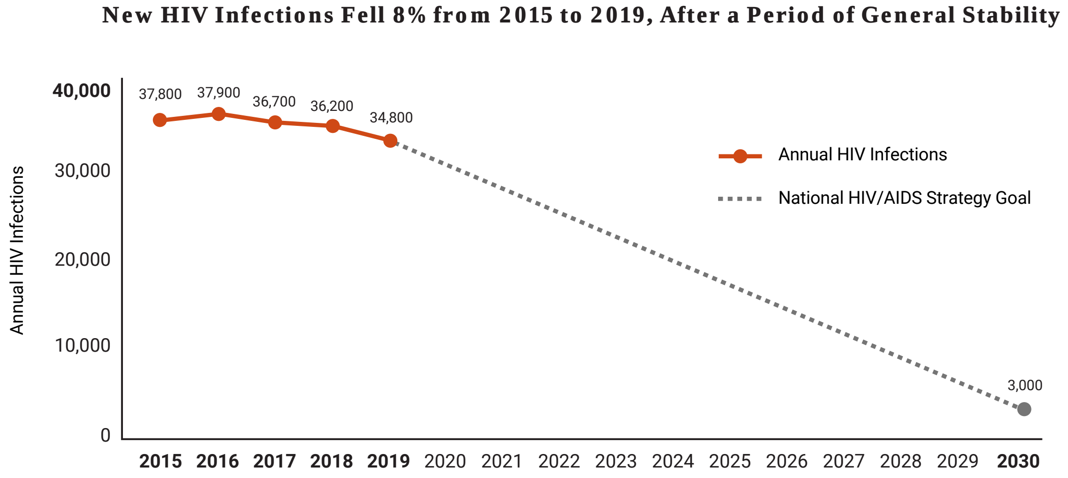

Figure 1. Annual HIV infections in the United States, 2015–2019

Despite this progress, important disparities persist. During this period, Black, Latino, and White gay and bisexual men and Black heterosexual women bore the greatest burden of new HIV infections.[11] (See Figure 2.)

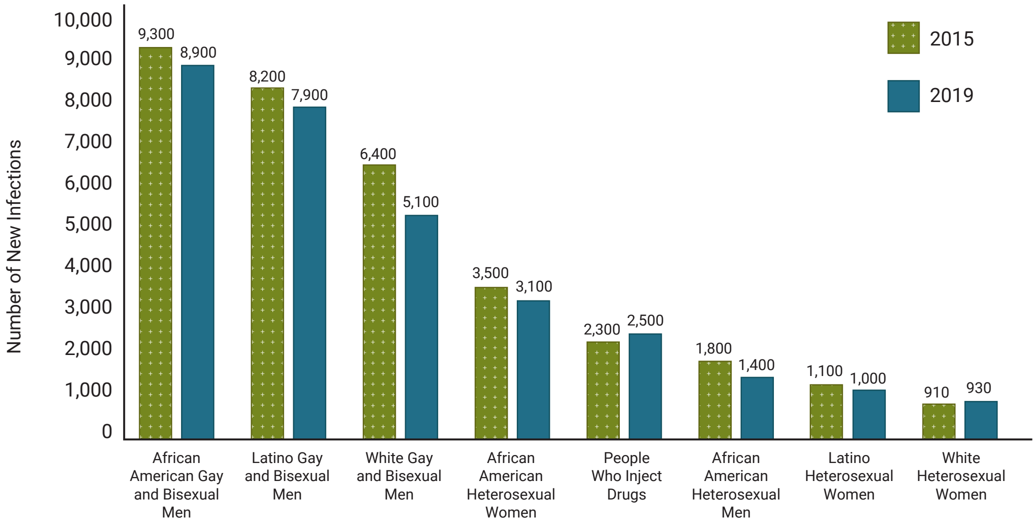

Figure 2. New HIV infections by most impacted populations, United States, 2015 vs. 2019[11]

EFFECTIVE TREATMENT AND PREVENTION ARE NOT ADEQUATELY REACHING PEOPLE WHO COULD BENEFIT MOST.

Although HIV remains a threat in every part of the United States, certain populations—and parts of the country—bear most of the burden, signaling where HIV prevention, care, and treatment efforts must be focused.

HIV by Population

Black and Latino communities are disproportionately affected by HIV compared to other racial/ethnic groups (see Table 1).

Table 1. Proportion of People with HIV by Race/Ethnicity Compared to Proportion of U.S. Population, 2019

Race/Ethnicity	% of People with HIV, 2019[11]	% of U.S. Population, 2019[14]
Black/African American	**40.3%**	**13.4%**
White	28.5%	60.1%
Hispanic/Latino	**24.7%**	**18.5%**
Asian	1.5%	5.9%
American Indian/Alaska Native	0.3%	1.3%
Native Hawaiian and Other Pacific Islander	0.09%	0.2%

The disproportionate impact of HIV among Black and Latino communities is also evident in incidence (new infections). (See Figure 3.)

* * * * *

The latest incidence estimates indicate that effective **prevention and treatment are not adequately reaching people who could benefit most.**

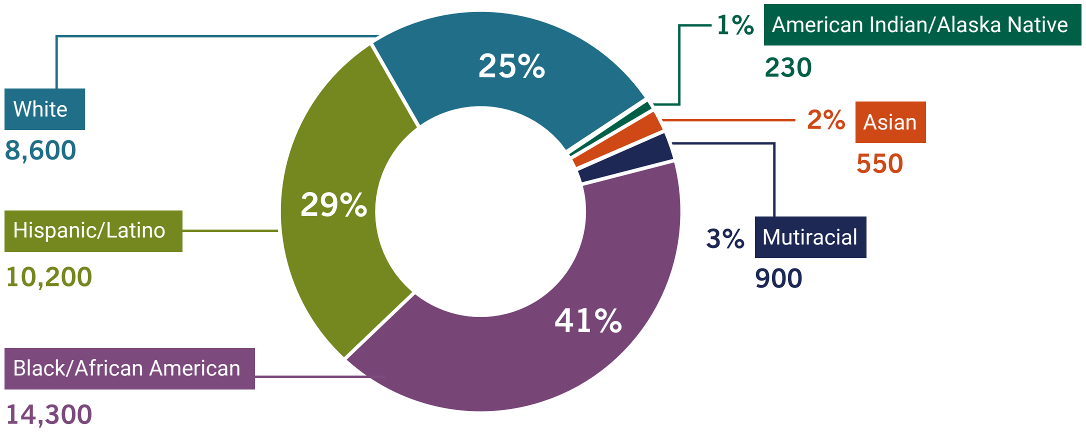

Figure 3. HIV incidence by race/ethnicity, 2019[11]

In all regions of the United States, gay and bisexual men are the most disproportionately affected group. They account for about 66% of new HIV infections each year, even though they account for only 2% of the population, with the highest burden among Black and Latino gay and bisexual men and young men.[11, 15] In 2019, 26% of new HIV infections were among Black gay and bisexual men, 23% among Latino gay and bisexual men, and 45% among gay and bisexual men under the age of 35.

Disparities persist among women. Black women are disproportionately affected compared to women of other races/ethnicities. Although annual HIV infections remained stable among Black women from 2015 to 2019, the rate of new HIV infections among Black women was 11 times that of White women and 4 times that of Latina women.[11]

Over 1 million people identify as transgender in the United States.[16] Adult and adolescent transgender people composed 2% (669) of new HIV diagnoses in the United States and dependent areas in 2019. Most of those new HIV diagnoses were among Black/African American people. Compared to all adults and adolescents with diagnosed HIV in 2019, transgender women had almost equal viral suppression rates, while transgender men had higher viral suppression rates.[2, 17, 18]

In 2019, youth aged 13–24 years composed 21% of the 36,398 new HIV diagnoses in the United States. Youth with HIV are the least likely of any age group to be retained in care and have a suppressed viral load.[3] However, in a national survey of students in grades 9–12 in the United States, significantly fewer students reported being tested for HIV in 2019 (9.4%) than in 2009 (12.4%). In addition, trends over the past 10 years (from 2009 to 2019) indicate significant decreases in the percentage of sexually active high school students who used condoms during last sexual intercourse (61.1% vs. 54.3%), and only 8.6% of sexually active students reported being tested for sexually transmitted infections (STIs) during the past year.[19] This despite the fact that almost half of the 26 million new STIs were estimated to occur in youth ages 15–24 in the United States in 2018.

In 2019, 7% of new HIV infections in the United States were among people who inject drugs (PWID). Men who inject drugs accounted for 4% of new HIV infections, and women who inject drugs accounted for 3%. Long-term declining trends in HIV incidence among people who inject drugs have stalled. For example, from 2015 to 2019, the number of new HIV infections remained stable among people who inject drugs.[11] Localized outbreaks have contributed to this trend. People who inject drugs are at high risk for acquiring hepatitis C virus infection, and, in fact, 62–80% of people who inject drugs and have HIV experience coinfection with HIV and hepatitis C.

HIV by Geography

Most of the nation's HIV diagnoses are concentrated in certain geographic areas, that is, urban areas and southern states. In 2016 and 2017, more than half of new HIV diagnoses were concentrated in geographic hotspots across the United States: 48 counties plus Washington, DC, and San Juan, Puerto Rico.[4] Seven states also have a substantial number of HIV diagnoses in rural areas.[20] These 57 jurisdictions are prioritized for the EHE initiative. Southern states account for 38% of the U.S. population but bear the highest burden of HIV infection with 53% of annual HIV infections, 46% of people with HIV, and 52% of people with undiagnosed infections.[11] (See Figure 4.)

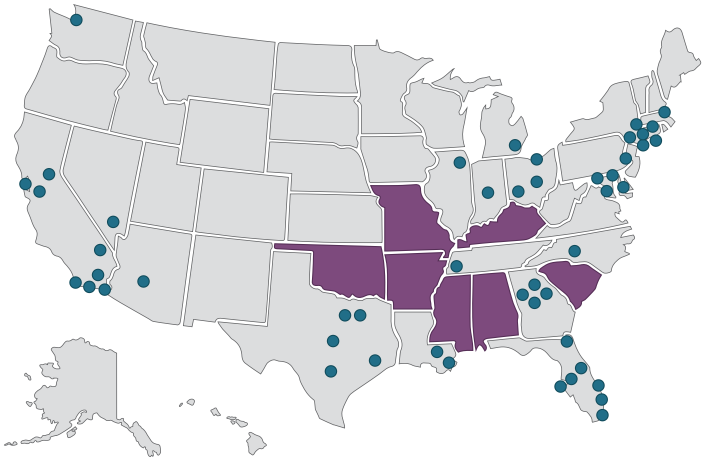

Figure 4. 57 jurisdictions prioritized in the *Ending the HIV Epidemic* initiative

This current landscape of HIV prevention, care, and treatment presents several opportunities and challenges that shape this 5-year Strategy.

OPPORTUNITIES

More tools than ever before are available to end the HIV epidemic in the United States. People who initiate ART soon after diagnosis and remain adherent can live long, healthy lives.[21] In addition, people with HIV who take ART and achieve and maintain an undetectable viral load have effectively no risk of transmitting HIV through sex.[22-25] Thanks to a robust toolbox that includes syringe services programs (SSPs), PrEP, and post-exposure prophylaxis (PEP), and treatment as prevention, an individual's risk of acquiring HIV is significantly lower than ever (see Figure 5).

* * *

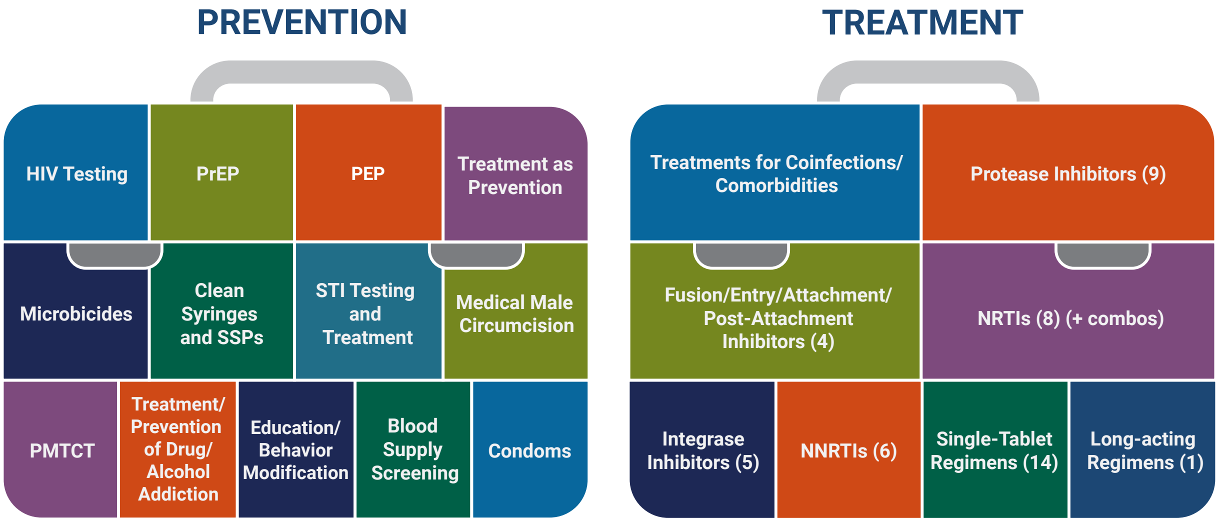

Figure 5. HIV prevention and treatment toolkits. Source: Eisinger et al.[26] Published by Oxford University Press for the Infectious Diseases Society of America 2019. This work is written by (a) U.S. Government employee(s) and is in the public domain in the U.S. Image modified with permission of authors.

To realize the full potential of these tools, several opportunities exist to expand the capacity of existing public health infrastructure, health care systems, and the health care and social service workforce. Engaging the diverse communities of people with and affected by HIV in planning for and delivery of HIV prevention and care services is essential. Further, expanding partnerships and training among traditional settings and parties, as well as identifying and working with nontraditional partners that are likely to engage people with or who experience risk for HIV, will better leverage the capacities of more interested parties and organizations to facilitate access to HIV diagnostics, prevention, care, treatment, and supportive services.

Importantly, the availability and use of data from a variety of sources, along with national, state, tribal, territorial, and local (and even clinic-level) indicators and targets, can help guide decision-making, service planning, and resource allocation.

Along with better use of data, ensuring that community-driven planning and decision-making include more diverse voices, expertise, and experiences can enhance how programs and services are tailored, implemented, and assessed to reach the populations that need them.

During the lifespan of this Strategy, other long-acting therapeutics and other simplified HIV drug regimens may become available. The overall value, potential impact, and cost-effectiveness of each new HIV testing, prevention, care, or treatment intervention must be demonstrated. Policy and program development should occur in parallel with the review and approval process for any new prevention or treatment options, such as long-acting injectable or implantable medications. These efforts should incorporate formative research and conversations with all relevant interested parties and organizations, especially patients, providers, and payers to identify challenges and opportunities to prevent gaps between the approval, implementation, and uptake stages.

Ongoing HIV research will facilitate progress toward HIV prevention and treatment, addressing of comorbid health conditions, and better understanding and addressing of HIV disparities and inequities, while advancing novel approaches toward long-term HIV remission and the ultimate goal of an HIV cure. Incorporating a strong implementation science framework in that research will support successful adaption and utilization of effective interventions that are acceptable to target communities.

These opportunities and developments, among others, will continue to transform and help guide the nation's approach to HIV through 2025.

BIOMEDICAL HIV PREVENTION TOOLS

PrEP is medicine that people who experience risk for HIV take to prevent getting HIV from sex or injection drug use.

PEP is HIV medicine used in emergency cases for people who have possibly been exposed to HIV. People must start taking the pill within 72 hours of exposure.

Treatment as Prevention is a highly effective prevention method in which people with HIV take HIV medication daily as prescribed and get and keep an undetectable viral load. As a result, they have effectively no risk of sexually transmitting HIV to their HIV-negative partners. This is often referred to as U=U or "undetectable = untransmittable."

CHALLENGES

Although the United States is making significant progress in improving HIV outcomes, significant challenges remain. Gaps in the HIV care continuum (see Figure 6) are driving HIV transmission. By ensuring that everyone with HIV is aware of their status, receives the treatment they need, and achieves and maintains viral suppression—key steps in the HIV care continuum—we can preserve the health of people with HIV, improve the quality of their lives, and drive down new HIV infections.

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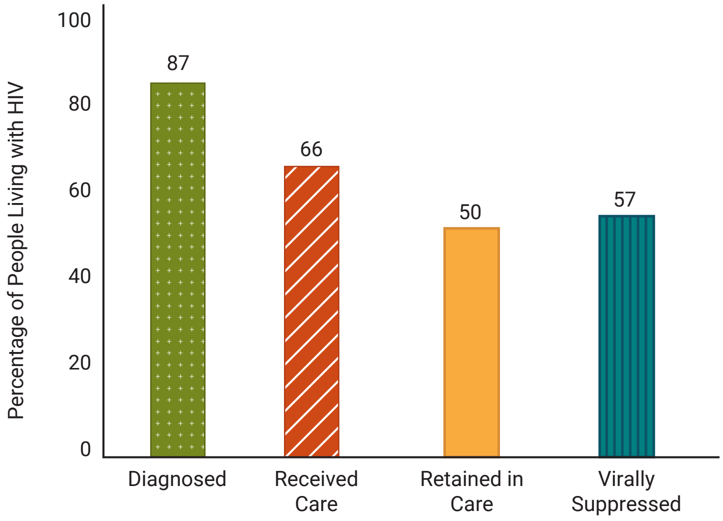


Figure 6. Prevalence-based HIV care continuum, United States, 2019[2]

The most recent data available (2019) show the following:

- Less than one-half (39%) of the U.S. population has ever been tested for HIV.[27] Of people with HIV, an estimated 158,500 (13%) were unaware of their status,[11] meaning they are not receiving the care they need to stay healthy and prevent transmission to others. The number unaware is especially high in the South, likely contributing to the high burden of HIV in the region.
- One in three people with HIV (34%) is not receiving needed HIV care.[2]
- Only 57% of people with HIV were virally suppressed, meaning that 43% are not receiving the benefits of HIV treatment.[2]

These gaps in the care continuum are challenges to be addressed because, according to a CDC transmission model based on 2016 data, approximately 80% of new HIV infections were transmitted from the nearly 40% of people with HIV who either do not know they have HIV or who received a diagnosis but are not receiving regular care (see Table 2).[28]

Table 2. HIV Transmissions in the United States, 2016

% of People with HIV	Status of Care	Accounted for X% of New Transmissions[a]
15%	Didn't know they had HIV	38%
23%	Knew they had HIV but weren't in care	43%
11%	In care but not virally suppressed	20%
51%	Taking HIV medicine and virally suppressed	0%

[a] Total does not equal 100% because of rounding. Source: CDC.[29]

In addition to these gaps in HIV diagnoses, care, and treatment, there are HIV prevention challenges. Only 23% of the approximately 1.2 million people indicated for PrEP are receiving it; in other words, about 3 in 4 people who could benefit from PrEP are not receiving it.[30] Further, significant disparities in PrEP coverage persist based on race/ethnicity, sex at birth, and age.[31, 32] Among those who initiate PrEP, daily pill adherence and long-term maintenance can be a challenge.[33, 34]

Although anyone can acquire HIV, the epidemic disproportionately affects specific populations, communities, and geographic areas across the United States. These disparities exist among gay, bisexual, and other men who have sex with men (MSM), especially Black, Latino,[*] and American Indian/Alaska Native men. They also exist among Black women, transgender women, youth (particularly gay and bisexual young men and transgender youth), and people who inject drugs. These gaps remain particularly troublesome not only among disproportionately affected populations, but also in some rural areas and the South. In 2019, it was estimated that more than one-half of new HIV infections occurred in the South.[11]

Inequities in the social determinants of health are significant drivers and contributors to health disparities and highlight the need to focus not only on HIV prevention and care efforts, but also on the ways that programs, practices, and policies affect communities of color and other populations that experience HIV disparities.

Persons from racial and ethnic minority groups are more likely to be uninsured compared to non-Hispanic Whites,[35] limiting their access to health care. Barriers to health care access include lack of transportation and childcare, inability to take time off work, experiences with housing instability or homelessness, communication and language barriers, racism, discrimination, and lack of trust in health care providers.

[*] For this Strategy, Black is defined as African American or Black, and Latino is defined as Latino or Hispanic.

Stigma is an attitude of disapproval and discontent toward a person or group because of the presence of an attribute perceived as undesirable.

Discrimination is often a consequence of stigma, occurring when unfair and often unlawful actions are taken against people based on their belonging to a particular stigmatized group.

Sexual and gender minorities also face health disparities.[36-40] Barriers to health care include stigma, discrimination, medical mistrust, safety, and lack of access to affirming mental health care.[41] Sexual and gender minorities face greater health challenges than heterosexual and cisgender people due in part to inequities such as stigma and discrimination.[37] Sexual and gender minority populations have lower levels of health insurance and access to regular health care compared to heterosexual/cisgender people.[42, 43]

Another threat to achieving national HIV prevention and care goals is the increase in drug use resulting from both the nation's opioid crisis and resurgent availability and use of methamphetamine and other stimulants among gay men and others who experience higher risk for HIV. Increases in drug use are linked to rising rates, and clusters, of several infectious diseases including hepatitis A, hepatitis B, hepatitis C, and HIV,[44] which threaten the progress to date to reduce HIV transmission, particularly among people who inject drugs. Recognizing this threat, in 2016 CDC identified 220 counties in 26 states that are vulnerable to HIV and viral hepatitis because of the opioid epidemic.[45] Many of those counties have taken steps to implement harm reduction services and strengthen their capacity to detect and respond to a potential outbreak. Half of the vulnerable counties were in the Appalachian region, where—along with other areas of the country—there have been multiple recent clusters and outbreaks of new HIV infections among people who inject drugs. Tailored technical assistance and support is needed to help these communities address the syndemic of HIV and hepatitis C virus fueled by substance use disorders. A particular focus should be on supporting them in resolving the local and state structural and systemic issues that get in the way of implementing evidence-based harm reduction and other services for the prevention of HIV and other infectious diseases and making best use of all available substance use disorder and infectious disease funding.

Using drugs or alcohol may lead to sexual behaviors (e.g., having sex without a condom, having multiple partners) that increase the risk of getting or transmitting HIV. In a recent large study of HIV-negative sexual and gender minorities who have sex with men, of whom a substantial proportion used crystal methamphetamine (crystal meth), this highly addictive drug emerged as the dominant risk factor associated with HIV seroconversion, with persistent methamphetamine users accounting for one-third of all observed HIV seroconversions in the study.[46] Further, a 2018 analysis of the National Notifiable Diseases Surveillance System found substantial overlap in reported substance use and sexual risk behaviors among primary and secondary syphilis cases.[47] For people with HIV, substance use can hasten disease progression and negatively affect care retention and treatment adherence.[48]

Rising rates of STIs also threaten efforts to reduce new HIV infections.[49] STIs are associated with a higher risk of transmitting or acquiring HIV.[50] A recent modeling analysis estimated that 7% of HIV infections were attributed to chlamydia, gonorrhea, syphilis, and trichomoniasis.[51, 52] Siloed program delivery leads to missed opportunities to screen, link, and provide navigation, care management, and treatment for people with HIV, STIs, viral hepatitis, and substance use and/or mental health disorders.

HIV, STIs, VIRAL HEPATITIS, AND SUBSTANCE USE DISORDERS—A HOLISTIC APPROACH TO THE SYNDEMIC

A syndemic is a set of linked health conditions—such as HIV, viral hepatitis, STIs, and alcohol and substance use and mental health disorders—that adversely interact with one another and contribute to an excess burden of disease in a population. Addressing a syndemic can be challenging because it requires the implementation of integrated and sometimes simultaneous prevention, screening, diagnosis, and treatment efforts, as well as the rapid application of new scientific advances. To be successful, these efforts must go beyond disease-specific responses to identifying and addressing root causes, with greater disease risk and poorer health outcomes often closely tied to employment, stable housing, access to health care and food, and other social determinants of health.

A **syndemic** is a set of linked health problems that interact synergistically and contribute to excess burden of disease in a population.

Social determinants of health and stigma also play a significant role in this syndemic.

A holistic approach to addressing the syndemic of HIV, viral hepatitis, STIs, and substance use and mental health disorders can only be effective if we also continue to explore the connection between mental health, experience of violence and other types of traumas, substance use, and infectious diseases. Past and present trauma, including experience of violence, homo- and transphobia, discrimination, and racism, contribute to the excess burden of disease in many communities at risk for or diagnosed with these health conditions. This burden challenges our collective efforts to provide prevention and care services because models of trauma-informed care are often not fully developed within many health care settings. In addition, ready access to substance use and mental health care, or health care in general, is lacking in many communities, exacerbating existing health disparities in communities of color.

The syndemic does not just appear in adulthood; the inter-relationship between sexual health, trauma, mental health, and substance use may have precursors in early childhood and coalesce in adolescence. Adverse childhood experiences have substantial effects on health and well-being through adolescence and into adulthood. In adolescence, sexual risk, substance use, experience of violence, and mental health problems co-occur and represent significant risk for STIs and HIV, particularly among sexual minority youth. The opportunity exists, however, to adopt trauma-informed approaches and bolster the coordination, capacity, and delivery of services to populations with and experiencing risk for these linked conditions.

To help drive a coordinated response to the syndemic, the Strategy complements the Viral Hepatitis National Strategic Plan (Viral Hepatitis Plan) and the Sexually Transmitted Infections National Strategic Plan (STI Plan), both released in early 2021. These plans mutually recognize that both the specific health conditions and the syndemic itself present opportunities to conduct relevant research and analyses, develop evidence-based interventions and policy options, and allocate resources to respond efficiently and effectively. The Strategy aligns with the Administration’s statement of first-year drug control priorities and will also align with the comprehensive 2022 National Drug Control Strategy being developed by the White House Office of National Drug Control Policy.

COVID-19 and the Syndemic

This Strategy is being released during the unprecedented COVID-19 pandemic. Since early 2020, SARS-CoV-2, the coronavirus that causes COVID-19 disease, has spread rapidly across the globe, causing more than 200 million confirmed cases worldwide and claiming the lives of more than 4 million individuals to date. The pandemic has caused great uncertainty, including for people with and who experience risk for HIV, STIs, viral hepatitis, and substance use and mental health disorders.

In the United States, the pandemic has exacerbated existing challenges in public health and health care systems, exposing longstanding and pervasive structural inequities. Many clinical and public health services focused on people with or who experience risk for HIV, viral hepatitis, STIs, and substance use and mental health disorders have been forced to reduce hours or close temporarily, with staff redeployed to address the public health emergency. These actions have particularly affected populations who are already disproportionately affected by these health conditions and who are most vulnerable to the economic and societal consequences of the pandemic, including loss of employment and insurance, the necessity to work in unsafe environments, housing and food insecurity, cutbacks to public transportation, lack of access to credible health information in multiple languages, and obstacles to practicing safe social distancing. Faced with these challenges, many individuals have not received necessary medical care or related services. Implementation of the Strategy should consider the potential long-term effects caused by these circumstances.

The Strategy accounts for the many lifesaving program innovations and policy changes that were developed to counteract the curtailment of in-person visits and other challenges posed by the COVID-19 pandemic. Examples include the use of telephone- and video-based telehealth visits to ensure that people who experience risk for HIV can access PrEP and that people with HIV can access ongoing care and treatment; exploration and implementation of tele-harm reduction approaches to substance use disorder treatment and HIV treatment; distribution of HIV self-tests and home specimen collection kits; multi-month dispensation of ART; condom delivery; and modification of policies to support mail order, home delivery, or curbside pick-up of medication. Further, community-based programs expanded their roles to ensure the safety of health care workers, clients, and community members by distributing timely and accurate information about COVID-19 testing and vaccinations; facilitating interactions with public health authorities; and serving as testing and vaccination sites.

These innovations in HIV prevention and care delivery prove that the nation can innovate and adapt to ensure that access to HIV prevention and treatment services continues uninterrupted—even in the presence of unprecedented circumstances. Although their outcomes must be studied, many of these innovations may prove worth sustaining as effective tools in our work to achieve our national HIV goals. Our tasks ahead are to carefully determine how to preserve these innovations over the long term for people who can benefit from them, adapt these innovations to achieve success with other populations, and leverage resources to deliver these innovations to larger audiences.

NATIONAL HIV/AIDS STRATEGY 2022–2025

This Strategy, updated for 2022–2025, builds on the lessons learned and progress of previous iterations and seeks to leverage opportunities and address the challenges that remain. It provides a national roadmap for continuing the coordinated response to HIV and puts the country on the path to end the HIV epidemic in the United States by 2030. The Strategy is guided by this vision statement:

The United States will be a place where new HIV infections are prevented, every person knows their status, and every person with HIV has high-quality care and treatment, lives free from stigma and discrimination, and can achieve their full potential for health and well-being across the lifespan.

This vision includes all people, regardless of age, sex, gender identity, sexual orientation, race, ethnicity, religion, disability, geographic location, or socioeconomic circumstance.

OVERVIEW

This Strategy includes the following:

- Four goals to achieve this vision, specific objectives for each goal, and strategies for each objective.
- Priority populations, identified by national-level data as being disproportionately affected by HIV, to help focus stakeholder efforts and resource allocation.
- Nine core indicators, one disparities indicator stratified for each priority population with quantitative targets to track progress toward achieving national HIV goals, and one developmental indicator to be established.

OBJECTIVES AND STRATEGIES

The Strategy sets forth four goals, objectives for each goal, and strategies for each objective (see Table 3 for definitions). These objectives and strategies are designed to guide federal partners as well as nonfederal parties in achieving the Strategy's vision and goals. The objectives provide direction for the attainment of each goal. The strategies recommend approaches to achieve the objectives. Numerous objectives and strategies could fit under more than one goal. However, each one has been placed under the goal with which it most closely aligns.

Table 3. Definitions of Elements of the Strategy

National HIV/AIDS Strategy	Federal Implementation Plan
Goals: Broad aspirations that enable a plan's vision to be realized **Objectives:** Changes, outcomes, and impact a plan is trying to achieve **Strategies:** Choices about how best to accomplish objectives	**Action Steps:** Specific activities that will be performed to implement the strategies and achieve the goals of the plan **Progress Reports:** Reports on progress, successes, and challenges

[a] Adapted from the HHS Office of the Assistant Secretary for Planning and Evaluation.

The Strategy's objectives and strategies are intended to be implemented by a broad mix of interested parties and organizations at all levels and across many sectors, both public and private. They also serve as a tool to foster a shared focus, enhance coordination of efforts across agencies and programs, and identify areas of synergy and new opportunities to sharpen collective efforts. The strategies are intended to be scalable by implementer type and size of population to be served.

INDICATORS

The Strategy adopts bold targets for ending the HIV epidemic in the United States by 2030, calling for a 75% reduction in new HIV infections by 2025 and a 90% reduction by 2030. The Strategy's goals, objectives, and strategies focus on achieving national targets set for 2025, setting the stage to ultimately end the HIV epidemic by 2030. As such, the Strategy's vision, goals, objectives, strategies, indicators, and quantitative targets align with the EHE initiative, which complements and will serve as one of many important implementation elements of the Strategy (see Box 1).

The Strategy includes indicators for measuring progress and quantitative targets for each indicator. There are nine core indicators, one of which is stratified to measure progress in addressing HIV disparities in the priority populations (i.e., disparities indicators). In addition, one key issue, quality of life for people with HIV, was designated as the subject for a "developmental indicator," meaning that data sources, measures, and targets will be identified, and progress monitored thereafter. The Strategy's indicators and quantitative targets also align with *Healthy People 2030*. A detailed discussion of the indicators, including methodology, and specifications is found in Appendix A.

BOX 1

THE NATIONAL HIV/AIDS STRATEGY AND THE *ENDING THE HIV EPIDEMIC IN THE U.S.* INITIATIVE

The Strategy and *Ending the HIV Epidemic in the U.S.* (EHE) initiative are complementary, with EHE serving as a leading component of the work by the U.S. Department of Health and Human Services (HHS), in collaboration with federal, state, tribal, territorial, and local partners, to end the HIV epidemic in the United States by 2030. Both the Strategy and the EHE initiative aim to reduce new HIV transmissions in the United States by 75% by 2025 and by 90% by 2030, which would mean fewer than 3,000 new HIV infections per year.

EHE efforts focus on 57 priority jurisdictions, including 48 counties, Washington, DC, and San Juan, Puerto Rico, where greater than 50% of new HIV diagnoses occurred in 2016 and 2017, as well as 7 states with a disproportionate occurrence of HIV in rural areas. With additional funding appropriated by Congress, HHS is providing the 57 geographic focus areas with an infusion of additional resources, expertise, and technology to develop and implement locally tailored EHE plans. Those plans, developed and being implemented with significant community involvement, focus on four pillars:

- Diagnose all people with HIV as early as possible.
- Treat people with HIV rapidly and effectively to reach sustained viral suppression.
- Prevent new HIV transmissions by using proven interventions, including preexposure prophylaxis (PrEP) and syringe services programs (SSPs).
- Respond quickly to potential HIV outbreaks to get prevention and treatment services to people who need them.

The scope of the Strategy extends to agencies beyond HHS and encompasses the entire nation. The Strategy presents a holistic approach to engaging a broad range of interested parties and organizations across many sectors of society to not only end the HIV epidemic by 2030, but also address other components of the syndemic, stigma, discrimination, and social determinants of health.

PRIORITY POPULATIONS

Although HIV affects people from all social, economic, and racial and ethnic groups, and from all parts of the United States, it disproportionately affects certain populations. The disproportionate prevalence of HIV in specific populations increases the risk for HIV transmission with each sexual or injection drug use encounter within those populations. In addition, a range of social, economic, and demographic factors—such as stigma, discrimination, socioeconomic status, income, education, age, and geographic region—affect people's risk for HIV or their ability to access or remain engaged in prevention or care services.

To focus effort and resources for the greatest impact, the Strategy uses national-level HIV surveillance data to identify populations disproportionately affected by HIV. The following factors were considered: (1) incidence of new HIV infections and trends; (2) prevalence of HIV; (3) HIV diagnoses; (4) outcomes along the HIV care continuum; and (5) potential impact of other major public health threats (e.g., opioid epidemic). Based upon this analysis, the Strategy prioritizes efforts to reduce disparities and improve HIV outcomes among

- gay, bisexual, and other men who have sex with men, in particular Black, Latino, and American Indian/Alaska Native men;

- Black women;
- transgender women;
- youth aged 13–24 years; and
- people who inject drugs.

Focusing efforts on these five priority populations will reduce the HIV-related disparities they experience, which is essential if the nation is to succeed on the path toward ending the HIV epidemic by 2030.

To drive action and measure progress toward reducing health inequities and disparities among the priority populations, the Strategy uses viral suppression, stratified by population, as an indicator. Viral suppression was selected as the disparities indicator because increasing and maintaining viral suppression among priority populations will improve health outcomes, reduce HIV-related deaths, and prevent new HIV transmissions. Monitoring progress on these disparities indicators also helps ensure that the nation is making progress with all populations, leaving no groups behind.

This Strategy acknowledges that other populations with unique circumstances warrant specific attention, such as sex workers, immigrants, older adults, people experiencing housing instability or homelessness, individuals with disabilities, and justice-involved individuals. For example, the risk of HIV among people who exchange sex for money, drugs, food, or shelter is high; however, little data exist for this population. The illegal—and often criminalized—nature of exchange sex complicates the collection of population-wide data on HIV risk among this population. Nevertheless, the high prevalence of HIV and STIs among people who participate in exchange sex warrants attention. Sex work is largely performed by transgender women, cisgender women, and men who have sex with men, and is also heavily concentrated among Black and African Americans. The convergence of gender, poverty, and racial and ethnic discrimination as social determinants of health within exchange sex must be examined further to fully understand the HIV epidemic.

Similarly, some non-U.S.-born people with or experiencing risk for HIV face unique challenges when accessing prevention, care, and treatment services. Discrimination, lack of culturally and linguistically competent service providers, and fear of interacting with health care systems and other authorities are often barriers to accessing needed services.

People involved in the justice system face a confusing/disparate system of prevention and care services, often for short time periods. These individuals experience a disproportionately high risk of HIV, as well as risk factors associated with under-utilization of prevention and treatment options, including substance use, mental health issues, and poor access to care.[53] Improving HIV prevention and management among justice-involved people requires innovative approaches to integrating care. HIV programs must work with state and local facilities to ensure that care services are provided throughout the justice system, particularly to people upon release back to their communities; pre- and post-transition planning is critical to decreasing barriers to care.

More than one-half of people diagnosed with HIV in the United States today are over age 50. Although an indicator of the success of modern HIV treatment, this statistic signals the need to tailor services to individuals within this population not only to continue their engagement in care and viral suppression but also to address the comorbidities and psycho-social needs often associated with aging.

Evidence suggests that some people with disabilities may experience higher risk of acquiring HIV than people who are not disabled. Some of the factors associated with this risk include poverty, vulnerability to sexual violence and abuse, limited access to education and health care, and social marginalization. Some people with disabilities may experience barriers to accessing the HIV prevention, testing, or care and treatment services they need.

People with HIV often have other disabilities, and people with disabilities can be at higher risk for acquiring HIV than the general population. Adopting syndemic approaches that place HIV in the context of multiply marginalized communities and that seek to comprehensively leverage a variety of health care, social services, and other community supports to improve overall community health offers an important opportunity to strengthen health care outcomes and improve the quality of life.

Local partners and interested parties should use local surveillance and program data on HIV—as well as on STIs, viral hepatitis, and social determinants of health—to identify the populations most affected in their communities and to understand the outcomes for each population along the continuums of HIV prevention and care. Each state, tribe, community, program, or clinic will make its own assessment of relevant priority populations so that programs and services can be tailored and focused accordingly. In some jurisdictions, local surveillance and program data may indicate that additional populations not mentioned here are experiencing persistent HIV disparities that require focus from local efforts.

In addition, some partners and organizations may work with specific populations or communities in a limited area with data that vary somewhat from the national data. For example, on a federal level, agencies such as the Indian Health Service, CDC's Division of Adolescent and School Health, Department of Veterans Affairs, Federal Bureau of Prisons, and Administration for Community Living serve distinct populations with or who experience risk for HIV. Likewise, state, tribal, territorial, and local jurisdictions, as well as schools and other institutions, may serve distinct populations. For these and other interested parties, efforts should be guided by an assessment of health disparities within their purview and/or jurisdiction to determine how best to focus available resources to achieve results with the greatest impact.

IMPLEMENTATION

A separate NHAS Federal Implementation Plan will be developed in early 2022 and will detail federal partners' plans and activities to implement the strategies set forth in this document. During development of that plan, the federal partners involved will explore opportunities to engage other federal departments or agencies that could expand services or that administer programs or support delivery of services that address social determinants of health and reduce health disparities and, as such, could make vital contributions to national efforts to end the HIV epidemic.

GOAL 1: PREVENT NEW HIV INFECTIONS

THE OPPORTUNITY

The most effective ways to reduce new HIV infections are to ensure timely diagnosis and engagement in care and treatment for people with HIV so that they achieve and maintain viral suppression and therefore cannot transmit the virus; target prevention resources to the places with the largest disease burden and the populations experiencing greatest risk; and ensure that the most effective prevention strategies are prioritized and widely implemented. An array of HIV prevention options, for use in combination or on their own, is available to people with or experiencing risk for HIV.

- **HIV treatment as prevention.** Evidence has definitively shown that people with HIV who achieve and maintain an undetectable viral load by taking HIV medication as directed will not sexually transmit the virus to an HIV-negative partner.
- **HIV testing and engagement in care.** Nearly 40% of people with HIV are unaware of their status or are diagnosed but not receiving care. In 2016, people unaware or not receiving care accounted for nearly 80% of new HIV infections in the United States.[28]
- **PrEP.** Because of the 2019 USPSTF recommendation that clinicians offer PrEP with effective ART to persons who are at high risk of HIV acquisition, as of January 2021 HHS requires most insurance plans to cover PrEP without copay or cost-sharing as a result of the preventive care provisions of the ACA. Implementation guidance issued in July 2021 clarified that this coverage also includes a range of clinical services as part of PrEP clinical care.[54, 55] In addition, in 2019 FDA approved a second PrEP drug for people assigned male at birth. A generic version of the original drug became available, increasing options for people who wish to use PrEP. Researchers are investigating a variety of non-vaccine HIV prevention products including long-acting injectable antiretrovirals, long-acting oral pills, vaginal rings, vaginal and rectal gels, and more. If found safe and effective and approved by FDA, these products would further expand the options in the prevention toolbox.
- **SSPs, medication for treatment of opioid use disorder, and other harm reduction services.** Nearly 30 years of research shows that comprehensive SSPs are safe, effective, and cost-saving; do not increase illegal drug use or crime; and play an important role in reducing the transmission of HIV, viral hepatitis, and other infections.[56] FDA has approved several different medications to treat alcohol and opioid use disorders. Certain medications for opioid use disorder relieve the withdrawal symptoms and psychological cravings resulting from opioid dependence. Research also shows that these medications and certain behavioral therapies can contribute to lowering a person's risk of contracting HIV or hepatitis C by reducing the potential for relapse. Appropriations language from Congress permits the use of funds from HHS, under certain circumstances, to support SSPs with the exception that funds may not be used to purchase needles or syringes. Multi-agency guidance was issued on this opportunity, and in 2020 CDC published a technical package on effective strategies and approaches for planning, design, and implementation of SSPs. The White

GOAL 1: PREVENT NEW HIV INFECTIONS

Objectives

1.1 Increase awareness of HIV

1.2 Increase knowledge of HIV status

1.3 Expand and improve implementation of safe, effective prevention interventions, including treatment as prevention, PrEP, PEP, and SSPs, and develop new options

1.4 Increase the diversity and capacity of health care delivery systems, community health, public health, and the health workforce to prevent and diagnose HIV

House Office of National Drug Control Policy also included several actions related to increasing access to SSPs in its first-year policy priorities, including authorizing the use of federal funds to purchase syringes and other supplies.[57] In addition, in October 2021, the HHS released the new HHS Overdose Prevention Strategy in which evidence-based harm reduction services, including SSPs, are prioritized as a key target area of action.[58]

- **PEP, condoms, and other effective prevention interventions.** PEP is a short course of HIV medicines taken very soon after a possible exposure to HIV to prevent the virus from taking hold in the body. PEP should be used only in emergency situations and must be started within 72 hours after a recent possible exposure to HIV. Correct condom use remains one of the most effective methods to reduce the risk of HIV transmission during sexual activity. The CDC and USPSTF recommend intensive behavioral counseling on ways to prevent STIs (including HIV) in all adolescents and adults at increased risk for STIs.

In addition, a range of HIV prevention or multipurpose prevention products are under development or regulatory review, which could result in even more HIV prevention tools becoming available within the 5-year span of this Strategy.

CHALLENGES

The following challenges hinder efforts to reduce new infections:

- HIV awareness remains too low.[59, 60]
- HIV testing and diagnosis opportunities are being missed (see Box 2).[61]
- STIs are surging in the United States (see Box 3).[62]
- A significant number of people with HIV are unaware of their status or are diagnosed in the later stages of their HIV disease.[3, 11]
- Retention in HIV care is suboptimal.[2]
- Uptake of PrEP is too low.[30, 63, 64]
- There are a range of policy, legal, and resource barriers that limit full implementation of SSPs, especially in the most needed areas.[65, 66]

BOX 2

MISSED OPPORTUNITIES FOR HIV DIAGNOSIS

Substantial numbers of people who are diagnosed with HIV and who had experienced high risk for HIV experienced missed opportunities for earlier diagnosis. For example, in one study, approximately one-half of newly diagnosed gay and bisexual men and people who inject drugs had been unaware of their infection until diagnosed during the study. They reported not being offered HIV testing by any health care provider despite having seen one within the past year.[61] Further, a retrospective study at an urban adolescent HIV clinic found that many youth recently diagnosed with HIV had prior primary and acute care encounters within the health care system but did not receive an HIV test.[67]

Other studies have highlighted missed opportunities by setting. For example, STI clinic patients experience increased risk for HIV, yet data from nine STI clinics across the United States revealed that three-quarters of STI clinic patients were not tested for HIV despite visiting the clinic within the past year.[68]

BOX 2
MISSED OPPORTUNITIES FOR HIV DIAGNOSIS *(CONTINUED)*

Similarly, more than two-thirds of missed opportunities for HIV diagnoses in a Louisiana health care system occurred at health care visits outside the primary care setting, including inpatient care, specialty care clinics, surgical specialties, ob-gyn visits, and emergency care facilities.[69] In addition, an infectious disease practice in New Jersey found that hospital emergency departments and subspecialty clinics were the two most common settings for missed testing opportunities, with between 37% and 45% of patients presenting with a new HIV diagnosis with an encounter in the institution in the year prior.[70] Dental facilities present another opportunity to provide point-of-care HIV screening and testing.[71] Pharmacies and retail clinics represent a vast, largely untapped potential for the delivery of HIV testing in settings that are more accessible and, for some people, less stigmatizing than traditional settings.[72] Finally, the Centers for Disease Control and Prevention recommends that HIV screening be provided upon entry into and before release from correctional settings and that voluntary (opt-out) HIV testing be offered periodically during incarceration.[73] Studies have shown that opportunities for HIV diagnosis and linking HIV-positive individuals with justice system involvement to community care after release are being missed in the majority of prison systems and jails.[74, 75]

COVID-19 testing and vaccinations also present an opportunity to diagnose people who are unaware of their HIV status. One hospital in an urban setting saw a “considerable increase in acute HIV diagnoses” when it linked HIV screening with COVID testing in emergency departments.[76]

Missed opportunities for HIV testing result in diagnosis delays, disease progression, and lack of access to HIV care and treatment. They also prolong the time a person is unaware of their infection, increasing the potential for HIV transmission. For care and treatment to effectively reduce HIV incidence, improved testing coverage and frequency are needed to ensure that a large proportion of cases are diagnosed and treated soon after infection occurs.

BOX 3
OPPORTUNITIES FOR ENHANCED HIV PREVENTION SERVICES IN STI SPECIALTY CLINICS

STI specialty clinics have been an important health care setting for people who may not otherwise have access to health care services, including those who are uninsured, and for people seeking low-barrier (e.g., nontraditional hours, walk-in or express appointments, low or no cost), expert, and confidential services. STI clinics serve people who may not be engaged in HIV prevention programs or the primary health care system for their STI and HIV prevention, care, and treatment.[77-79] As such, they are suitable settings to (1) reach people who could benefit from HIV pre-exposure prophylaxis (PrEP) and nonoccupational post-exposure prophylaxis (PEP), including people diagnosed with an STI; and (2) identify people with HIV who are either unaware of their status or are not virally suppressed and could benefit from linkage to or reengagement in care.[80]

An evaluation of HIV testing events funded by the Centers for Disease Control and Prevention provided further evidence of STI clinics' important role in identifying people who experience increased risk for HIV. In 2019, STI clinics provided almost one-third of all CDC-funded HIV tests conducted among health care settings, and approximately 20% of all newly identified HIV-positive persons were diagnosed in STI clinics.[81]

SUMMARY OF OBJECTIVES

The following objectives are critical to achieving the goal of preventing new HIV infections:

1.1 Increase awareness of HIV

1.2 Increase knowledge of HIV status

1.3 Expand and improve implementation of safe, effective prevention interventions, including treatment as prevention, PrEP, PEP, and SSPs, and develop new options

1.4 Increase the diversity and capacity of health care delivery systems, community health, public health, and the health workforce to prevent and diagnose HIV

OBJECTIVES AND STRATEGIES

Objective 1.1 Increase awareness of HIV

Nearly four decades into the HIV epidemic, too many people still lack essential information about HIV or hold misconceptions about the virus, including how it is prevented and transmitted. The resulting misperception of self-risk and perpetuation of HIV-related stigma and discrimination can deter people from learning their status, accessing prevention services, seeking or remaining in care, or supporting people who need diagnostic, prevention, care, or treatment services.

More must be done to increase HIV awareness among everyone, but especially among people, communities, and the health workforce where HIV is most heavily concentrated. Messaging must be clear, specific, consistent, and culturally and linguistically appropriate and must reflect today's scientific knowledge of HIV disease progression, its impact on community and individual health, the importance of early and sustained HIV treatment, and the health and prevention benefits of viral suppression. Once developed, the messaging should be broadly and persistently disseminated as educational campaigns using both traditional and social media delivered by trusted community members and community influencers.

School-based health programs that include sexual health education and connect youth to services serve to create safer and more supportive school environments, particularly for LGBTQI+ youth.[82] These environments help prevent HIV among adolescents by providing students with the knowledge and skills to help them be healthy and avoid HIV. Comprehensive school-based health programs ensure that students can access the services they need, and promote protective factors, such as school connectedness, that have long-term impact on risk for HIV. HIV prevention implemented in schools includes curricula that are medically accurate, developmentally appropriate, affirming, culturally relevant, accessible, and universally designed with content and skills that target key behavioral outcomes and promote healthy sexual development. Efforts to improve the safety and supportiveness of school environments include the provision of policies and practices that support LGBTQI+ students as well as activities that increase school connectedness and parent engagement.

Suitable primary prevention approaches focused on youth should be age-appropriate, linguistically and culturally informed, community-centered, accessible and universally designed, inclusive, stigma-reducing, and grounded in science and medicine. According to the American Academy of Pediatrics, developmentally appropriate and evidence-based education about human sexuality and sexual reproduction provided over time by pediatricians, schools, other professionals, and parents is important to help children and adolescents make informed, positive, and safe choices about healthy relationships, responsible sexual activity, and their reproductive health.[83] Similar recommendations were presented in a 2021 report issued by the National Academies of Sciences, Engineering, and Medicine, which called for the adoption of a holistic sexual health paradigm, among other actions, to reduce STIs.[84] School-based programs that use strategies to increase sexual health education, connect youth to needed services, and increase the safety and supportiveness of school environments have been demonstrated to reduce sexual risk behavior, experience of sexual violence, and substance use.[83] Primary prevention should be a part of comprehensive sexual education, particularly for youth, including delayed initiation of sexual activity for those who are not yet sexually active, and non-judgmental and affirming information about safer sexual activity for those who are sexually active.

These efforts must engage organizations and people who shape and influence knowledge, attitudes, beliefs, and behaviors, particularly among populations that experience risk of HIV, as well as leverage digital strategies and new technologies to reach the highest number of people at relevant access points.

Strategies

1.1.1 Develop and implement campaigns, interventions, and resources to provide education about comprehensive sexual health; HIV risks; options for prevention, testing, care, and treatment; and HIV-related stigma reduction.

1.1.2 Increase knowledge of HIV among people, communities, and the health workforce in geographic areas disproportionately affected.

1.1.3 Integrate HIV messaging into existing campaigns and other activities pertaining to other parts of the syndemic, such as STIs, viral hepatitis, and substance use and mental health disorders, as well as in primary care and general wellness, and as part of annual reproductive health visits and wellness visits.

Objective 1.2 Increase knowledge of HIV status

In addition to general knowledge about HIV, it is important for people with HIV to receive a diagnosis (also known as knowledge of HIV status), which would allow them to take control of their health. Full implementation of CDC and USPSTF screening and testing guidelines is critical to increasing knowledge of status (see Box 4). Innovative models and approaches that expand access to and availability of testing in various settings such as routine opt-out testing in clinical settings, testing in retail pharmacies, self-testing, testing in correctional facilities, mobile testing, and self-testing offered via social networks are required. Early detection coupled with prompt linkage to care and immediate initiation of treatment is also critical and can lead to improved individual and community health outcomes. The U.S. Department of Veteran Affairs (VA) provides an innovative solution in which pharmacists developed a clinical dashboard that lists patients needing action, including a shared electronic medical record to span HIV, STI, viral hepatitis, and PrEP needs of VA patients. The dashboard enables staff to access quality improvement data, benchmarks against other comorbidities, and comparative analysis by year for improvement purposes.

BOX 4
HIV TESTING RECOMMENDATIONS

U.S. Preventive Services Task Force (USPSTF) Recommendation (2019)—USPSTF recommends that clinicians screen for HIV in adolescents and adults aged 15–65 years. Younger adolescents and older adults who experience increased risk of infection should also be screened. USPSTF also recommends that clinicians screen for HIV infection in all pregnant women, including those who present in labor or at delivery with unknown HIV status. Read the recommendation.

Centers for Disease Control and Prevention (CDC) Recommendations (2006)—CDC recommends that everyone aged 13–64 years get tested for HIV at least once as part of routine health care. For those with specific risk factors, CDC recommends testing at least annually. Read the recommendations.

Expansion of the status-neutral approach to HIV care allows for ongoing engagement in HIV prevention, care, and treatment regardless of a person's HIV status (see Box 5). Embracing a status-neutral approach helps improve care and service provision and eliminates structural HIV and other intersecting stigma by meeting people where they are, offering a "whole person" approach to care, and putting the needs of the person ahead of their HIV status. By embedding HIV prevention and care into routine care, this approach advances health equity by integrating HIV prevention and care with strategies that address social determinants of health and barriers to accessing and remaining engaged in care. HIV testing serves as the entry point to services—the pathway to prevention and treatment. In addition, people are assessed for and engaged in continuous care and supportive services if needed to improve health and prevent new infections (see Figure 7). Health care providers and public health partners play critical roles in a status-neutral approach.

Strategies

1.2.1 Test all people for HIV according to the most current USPSTF recommendations and CDC guidelines.

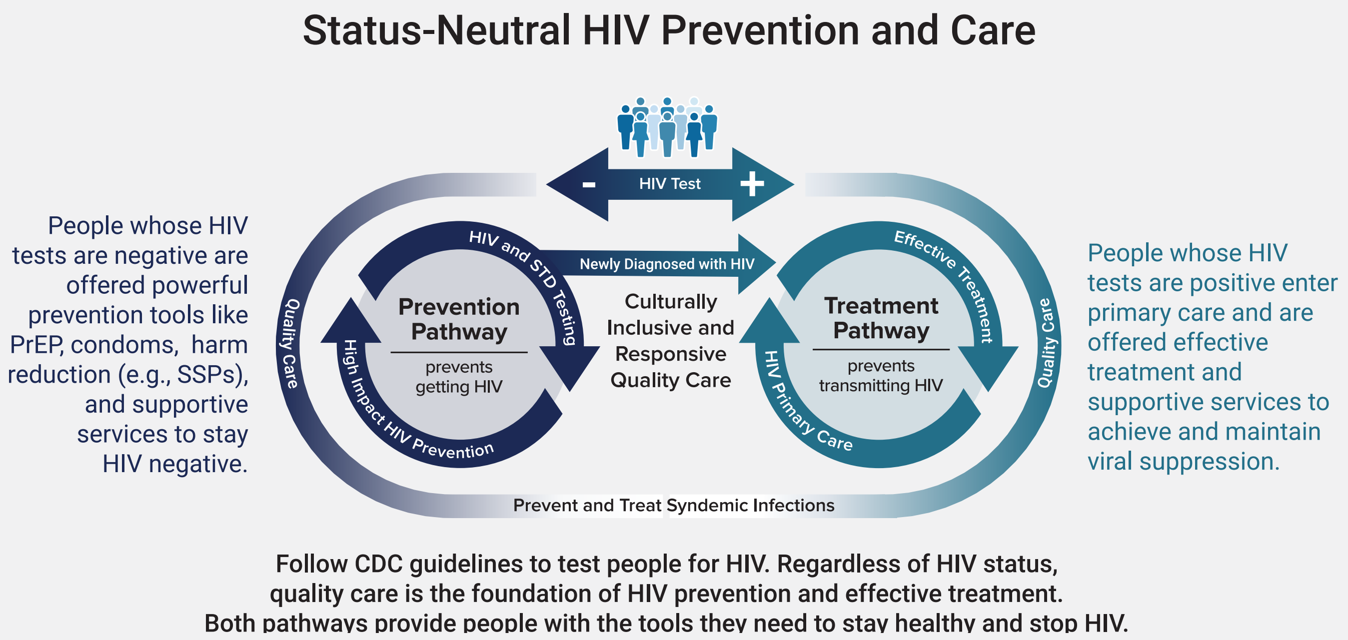
1.2.2 Develop new and expand implementation of effective, evidence-based or evidence-informed models for HIV testing that improve convenience and access.

1.2.3 Incorporate a status-neutral approach to HIV testing, offering linkage to prevention services for people who test negative and immediate linkage to HIV care and treatment for those who test positive.

1.2.4 Provide partner services to people diagnosed with HIV or other STIs and their sexual and/or syringe-sharing partners.

BOX 5
STATUS-NEUTRAL APPROACH TO HIV SERVICES

Adoption of a status-neutral approach to HIV services—in which HIV testing serves as an entry point to services regardless of positive or negative result—can improve testing as well as prevention and care outcomes.



People whose HIV tests are negative are offered powerful prevention tools like PrEP, condoms, harm reduction (e.g., SSPs), and supportive services to stay HIV negative.

People whose HIV tests are positive enter primary care and are offered effective treatment and supportive services to achieve and maintain viral suppression.

Follow CDC guidelines to test people for HIV. Regardless of HIV status, quality care is the foundation of HIV prevention and effective treatment. Both pathways provide people with the tools they need to stay healthy and stop HIV.

Figure 7. CDC's HIV status-neutral approach to HIV services

People who receive a negative HIV test result are offered powerful tools that prevent HIV, which may include pre-exposure prophylaxis (PrEP) and information about access to condoms and sexual health and harm reduction services. The prevention pathway emphasizes a consistent return to HIV testing and facilitates seamless entry to treatment for people who later receive a positive test result.

People who receive a positive HIV test result should be quickly engaged in HIV primary care and prescribed effective treatment to help them achieve and maintain an undetectable viral load and to tend to their other non-HIV-related health care. An undetectable viral load essentially eliminates the risk of sexual HIV transmission and enables people with HIV to live long, healthy lives.

Objective 1.3 Expand and improve implementation of safe, effective prevention interventions, including treatment as prevention, PrEP, PEP, and SSPs, and develop new options

Today, a range of highly effective prevention methods are available for use in combination or on their own. However, they do not yet reach everyone who needs them. Scaling up combinations of scientifically proven, cost-effective interventions targeted to the right populations in the right geographic areas is key to preventing new HIV infections. Especially important is scaling up highly effective, biomedical interventions: treatment as prevention (U=U), PrEP, and PEP, along with other highly effective prevention interventions including delayed initiation of sexual activity, correct and consistent condom usage, HIV and viral hepatitis testing, STI testing and treatment, SSPs and harm reduction services, universal HIV testing and linkage to care in primary care settings, and behavioral health services.[85-89]

These interventions must be available to people who need them in a variety of traditional health care and public health settings as well as nontraditional settings. Public health and health care systems can better meet the HIV prevention needs of the people they serve by developing or adopting culturally competent, linguistically appropriate, and accessible approaches and policies for service design and delivery. Examples of interventions include models that allow for low-barrier access to prevention and supportive services such as expanded service hours, drop-in appointments, telehealth, peer navigators, community health workers, and co-located service delivery.[90]

Schools can offer on-site sexual health services through their own health care infrastructure, such as school-based health centers and school nurses, or can establish referral systems to community partners to provide services, such as periodic, school-wide HIV and STI screening events or mobile clinics. In addition, treatment for alcohol use disorder, other substance use disorders, and mental health conditions can also reduce HIV.[91]

Policy and other systemic changes can support the expansion or improvement of these prevention interventions and can often be cost-neutral or cost-saving, as resources are realigned and services are provided at focused hours and delivery is tailored to people seeking assistance.[92] For example, structural barriers such as state or local laws or policies may require review and revision to facilitate expanded access to HIV prevention services, such as permitting SSPs, working with law enforcement to strengthen training on harm reduction as an effective public health intervention, or expanding prescribing authority and reimbursement of services for PrEP and PEP to pharmacists and other providers.

Ongoing implementation research on how best to use new and existing HIV prevention tools is needed, as is continued research into new tools that make HIV prevention more convenient and accessible. Research must pursue biomedical interventions that simplify implementation, such as long-acting, extended-release tools that can protect against HIV infection without daily pills, as well as non-systemic tools that expand user options such as lubricant- or douche-based microbicides or multi-purpose tools that might protect women from both HIV and pregnancy. Research is needed to identify strategies to most effectively integrate such tools into HIV prevention services when they become available. Other prevention tools also warrant further investigation, including antibody-mediated protection strategies, effective vaccines, and behavioral and social-structural interventions.

Strategies

1.3.1 Engage people who experience risk for HIV in traditional public health and health care delivery systems, as well as in nontraditional community settings.

1.3.2 Scale up treatment as prevention (i.e. U=U) by diagnosing all people with HIV, as early as possible, and engaging them in care and treatment to achieve and maintain viral suppression.

1.3.3 Make HIV prevention services, including condoms, PrEP, PEP, and SSPs, easier to access and support continued use.

1.3.4 Implement culturally competent and linguistically appropriate models and other innovative approaches for delivering HIV prevention services.

1.3.5 Support research into the development and evaluation of new HIV prevention modalities and interventions for preventing HIV transmissions in priority populations.

1.3.6 Expand implementation research to successfully adapt evidence-based interventions to local environments to maximize potential for uptake and sustainability.

Objective 1.4 Increase the diversity and capacity of health care delivery systems, community health, public health, and the health workforce to prevent and diagnose HIV

Expanding awareness, access, uptake, and adherence to effective HIV prevention interventions and improving availability of HIV testing for people with undiagnosed infection or ongoing risk of acquisition are actions that fall largely under the purview of the health care and public health systems. Therefore, steps must be taken to strengthen and expand capacity to ensure that these services are more commonly available in clinical and nonclinical settings including primary care, health centers, community-based organizations, emergency departments, pharmacies (see Box 6), Title X family planning sites, STI specialty clinics (see Box 3), substance use disorder treatment facilities, correctional settings, home- and community-based services, and other settings.

One step involves training all staff, ranging from those performing administrative duties to those delivering direct care, on trauma-informed care, cultural competency, stigma and discrimination, and unrecognized bias. Health care services that are respectful of and responsive to the health beliefs, practices, and cultural, developmental, and linguistic needs of diverse patients can also help bring about positive health outcomes.[93] Another step involves providing resources, incentives, training, and technical assistance to organizations to expand workforce and systems capacity especially in areas with limited availability of prevention and other health care and supportive services.[94] Available mechanisms to increase the number of HIV providers include health professions training grants, the National Health Service Corps Scholarship and Loan Repayment Programs, financial incentives to compensate providers for HIV care management, and program coordination so that providers who are not HIV specialists are adequately equipped to provide prevention services to high-risk populations and link patients who test positive to HIV clinical care providers.

These efforts must seek to expand the number, variety, diversity, and distribution of health care providers who routinely provide HIV testing, prevention counseling, and linkage to specialty care. A recent study showed that a low proportion of primary care providers were familiar with PEP and PrEP.[95] In some settings, these efforts require addressing the "purview paradox," a contradiction in which primary care physicians and HIV specialists sometimes consider PrEP to be beyond their purview.[96] Thus, HIV prevention and testing must become the purview of providers of all types who care for patients who may experience risk. Further, health care providers in high HIV prevalence jurisdictions must understand the relationship of epidemiological context and HIV acquisition. In these jurisdictions, providers may be encouraged to offer universal opt-out HIV testing and integrate PrEP screening as a part of routine care for all clients.

The nation's more than 13,500 health center service delivery sites span every U.S. state, U.S. territory, and the District of Columbia, and serve 1 in 11 people across the country. In 2020, health centers logged nearly 2.5 million visits for HIV tests and provided more than 389,000 people with access to PrEP.[97] Further strengthening and supporting the capacity of health centers to respond to the needs of individuals experiencing risk for HIV or living with HIV, including creating affirming and welcoming environments and providing HIV services with integrated behavioral health and family support models, is a promising approach to increasing availability of high-quality HIV prevention and care services for those who need them.

BOX 6
PHARMACISTS' ROLES IN HIV PREVENTION AND CARE

Pharmacists' knowledge and accessibility in nearly every urban and rural community can be leveraged as part of a comprehensive HIV prevention and care strategy to expand access to care and improve population health. As trusted health care professionals, pharmacists develop a strong rapport with patients and may be the key to addressing current disparities in PrEP-prescribing patterns as well as serving as an essential liaison between patients and other members of the multidisciplinary care team.[98] Pharmacists and community pharmacies can also be utilized to expand rapid, point-of-care HIV testing in communities.[72] In addition, studies have shown that engaging pharmacists as key players in a care team can increase retention in care and adherence to ART and maintain viral suppression.[99-101]

Strategies

1.4.1 Provide resources, incentives, training, and technical assistance to expand workforce and systems capacity to provide or link clients to culturally competent, linguistically appropriate, and accessible HIV testing, prevention, and supportive services especially in areas with shortages that are geographic, population, or facility based.

1.4.2 Increase the diversity of the workforce of providers who deliver HIV prevention, testing, and supportive services.

1.4.3 Increase the inclusion of paraprofessionals on prevention teams by advancing training, certification, supervision, financing, and team-based care service delivery.

1.4.4 Include comprehensive sexual health and substance use prevention and treatment information in curricula of medical and other health workforce education and training programs.

Indicators of Progress

Working together to pursue these objectives, the nation can achieve the following targets by 2025:

Indicator 1 Increase knowledge of status to 95% from a 2017 baseline of 85.8%.

Indicator 2 Reduce new HIV infections by 75% from a 2017 baseline of 37,000.

Indicator 3 Reduce new HIV diagnoses by 75% from a 2017 baseline of 38,351.

Indicator 4 Increase PrEP coverage to 50% from a 2017 baseline of 13.2%.

GOAL 2: IMPROVE HIV-RELATED HEALTH OUTCOMES OF PEOPLE WITH HIV

THE OPPORTUNITY

Starting and staying on HIV treatment as soon as possible following HIV diagnosis is necessary for all people with HIV to improve health outcomes and to prevent HIV transmissions.[102-104] People who start HIV treatment early and remain adherent to antiretroviral medications can live a normal lifespan. Improving the health of people with HIV requires continued focus on the HIV continuum of care to identify gaps and disparities at each step of the continuum to target resources and interventions (see Figure 8). Increasing access to comprehensive health care through expansion of Medicaid programs, counseling about private insurance through the Affordable Care Act and the American Rescue Plan, and implementing programs to support maintaining insurance such as co-pay and premium assistance through the RWHAP will increase access.

Figure 8. The HIV care continuum outlines the steps that people with HIV take from diagnosis to achieving and maintaining viral suppression. Source: HIV.gov.[105]

One common gap is the lack of understanding about the personal and public health benefits of entering treatment immediately and achieving and maintaining viral suppression. Increasing HIV education and available treatment along with strengthening relationships between patients and providers can play an even larger part in supporting people with HIV to begin, or reengage in, care and treatment and improve long-term health outcomes. Developing and expanding partnerships between providers of HIV specialty care and other providers (such as primary care and other health care providers as well as community organizations, health departments, community-based substance use and harm reduction programs, jails and prisons, and others) can leverage existing resources, allowing for seamless transitions between each step of the continuum from diagnosis to achieving and maintaining viral suppression. In addition, government, academic, and pharmaceutical industry research has provided simpler, more easily tolerated therapies than the initial generation of effective antiretroviral therapies. Continued advances such as long-acting injectables could result in the introduction of new HIV treatments during the course of this 5-year plan. These new options could help address challenges with adherence to a daily pill regimen.

Several approaches exist to support treatment initiation and adherence as well as retention in care across the continuum, including:

- **Rapid start programs.** Programs focusing on the immediate (ideally same day or within 7 days after diagnosis) initiation of ART have demonstrated success and are expanding in communities across the nation. Such “rapid start” or “red carpet” programs require structural or other changes to improve linkage to care, care coordination, patient navigation, adequate staffing, specialized services, and clinical provider evaluation.
- **Evidence-based strategies.** Every year evidence-informed best practices are added to the compendia of recommended interventions designed to improve treatment adherence and retention in care. Although interventions are often not a one-size-fits-all approach, health departments, clinics, and community organizations have additional tools to implement and receive a wide range of adaptations that have worked in different settings, in different population sizes, and for specific populations. Increasing the use of evidence-based strategies and best practices, coupled with community input, to reengage people who have fallen out of care, and people never in care, is necessary.
- **Health literacy.** Limited health literacy is associated with poorer health outcomes.[106] At all levels, further effort is needed to construct organizations, institutions, systems, and a workforce that embrace and implement the concepts and principles of health literacy. Efforts to create more health-literate public and private health systems at the federal, state, tribal, territorial, and local levels will help patients understand the health care system and the importance of HIV prevention, care, and treatment, and the benefits of viral suppression. Patient education is a necessary aspect of people-centered care, but it requires systems and providers to end the use of jargon, take the time to educate and explain in plain language, alter websites and brochures, proactively counter medical misinformation, use social media differently, and consider other culturally appropriate and accessible ways to deliver key information. Understanding HIV, the importance of treatment, and the risks of transmission to others can also lead to less stigma and shame, which in turn can lead to increased interactions with the health system and positive health outcomes.[107] Efforts to increase health literacy can also aid in addressing the mistrust of the medical system prevalent among many minority groups because of the historical systemic racism in many health care settings.

GOAL 2: IMPROVE HIV-RELATED HEALTH OUTCOMES OF PEOPLE WITH HIV

Objectives

2.1 Link people to care immediately after diagnosis and provide low-barrier access to HIV treatment

2.2 Identify, engage, or reengage people with HIV who are not in care or not virally suppressed

2.3 Increase retention in care and adherence to HIV treatment to achieve and maintain long-term viral suppression and provide integrative HIV services for HIV-associated comorbidities, coinfections, and complications, including STIs

2.4 Increase the capacity of the public health, health care delivery systems, and health care workforce to effectively identify, diagnose, and provide holistic care and treatment for people with HIV

2.5 Expand capacity to provide whole-person care to older adults with HIV and long-term survivors

2.6 Advance the development of next-generation HIV therapies and accelerate research for HIV cure

- **Comprehensive array of clinical and support services.** Current systems of HIV care and treatment have produced tremendous results, and the nation has more providers treating people with HIV than ever before. Today, people with HIV who are on treatment are living longer and healthier lives, and more than one-half of the people with HIV in the United States are over age 50. Researchers and clinicians are identifying and providing services to address the comorbidities experienced by people aging with HIV as well as people with HIV across the entire lifespan whose health can be impacted by noncommunicable comorbidities or coinfections. Other key population groups, such as youth, transgender people, people with substance use disorders, justice-involved people, people with disabilities, or people experiencing homelessness, require different combinations of tailored services to help improve their health outcomes.[108] Work continues to scale up evidence-based and evidence-informed programs that provide enhanced case and care management for people with HIV specific to their comorbidities or co-occurring conditions such as homelessness, food insecurity, and lack of employment.

- **Capacity of the health care delivery system.** As providers engage and reengage people in care and implement rapid start models, the number of people in care will increase. However, workforce needs may not be able to keep pace. The existing highly skilled and dedicated workforce, combined with a growing number of federally funded health centers of all types treating people with HIV, are key to ensuring positive health outcomes. There is an opportunity to examine ways to restructure staff and clinic workflows, implement technological solutions, enhance quality improvement programs, consolidate paperwork requirements, and examine task sharing to create new efficiencies and revamp the ability to use peers in key places along the HIV care continuum. Continuing to find innovative ways to encourage clinical and nonclinical providers to specialize in HIV care and treatment and engaging primary care providers in care and treatment of HIV, viral hepatitis, and STIs will remain important.
- **Meaningful involvement of people with HIV in program design and implementation.** People with HIV are central to the response to the epidemic and must be included in all elements of programming and service delivery to achieve the Strategy's goals. People with HIV must be included in program design and implementation, quality improvement initiatives, and campaigns; engaged as peers in prevention and care services; employed in HIV service delivery organizations; and involved in large-scale structural and policy initiatives. COVID-19 has presented opportunities for engaging people with HIV and communities in new and different ways, and program implementers must continue to create mechanisms for the meaningful engagement of interested individuals.

CHALLENGES

The following challenges hinder efforts to improve HIV-related health outcomes:

- Health care capacity and workforce shortages exist in critical geographic areas, particularly in the Southern United States.
- Services to address intersecting conditions of mental health, substance use disorders, homelessness or housing instability, and incarceration are limited and/or fragmented.
- HIV-related stigma, other forms of stigma associated with people with HIV, and discrimination continue to impede optimal health outcomes for people with HIV.
- There is a need for new and innovative health care delivery strategies and therapeutics to better support and retain people most vulnerable to not adhering to or dropping out of care.
- There is a lack of ongoing, diverse, meaningful, and engaged community input in some HIV programs and services.
- Medical mistrust and medical misinformation must be addressed.
- Lack of Medicaid expansion, particularly in Southern states disproportionately affected by HIV, limits access to HIV prevention and care services for many who need them.

SUMMARY OF OBJECTIVES

A concerted national effort to engage people with HIV in care is essential to achieving the Strategy's vision. The following steps are critical to achieving success:

2.1 Link people to care immediately after diagnosis and provide low-barrier access to HIV treatment.

2.2 Identify, engage, or reengage people with HIV who are not in care or not virally suppressed.

2.3 Increase retention in care and adherence to HIV treatment to achieve and maintain long-term viral suppression and provide integrative HIV services for HIV-associated comorbidities, coinfections, and complications, including STIs.

2.4 Increase the capacity of the public health, health care delivery systems, and health care workforce to effectively identify, diagnose, and provide holistic care and treatment for people with HIV.

2.5 Expand capacity to provide whole-person care to older adults with HIV and long-term survivors.

2.6 Advance the development of next-generation HIV therapies and accelerate research for HIV cure.

OBJECTIVES AND STRATEGIES

Objective 2.1 Link people to care immediately after diagnosis and provide low-barrier access to HIV treatment

Achieving improved health outcomes for people with HIV begins with ensuring that they are promptly linked to effective HIV care and treatment upon diagnosis. Linkage to HIV care and treatment immediately or as early as possible following HIV diagnosis leads to faster time to viral suppression, increased rates of retention in care and ongoing viral suppression, and reduction in transmission risk.[109-111] Programs must continue to build capacity and shrink the amount of time between diagnosis and linkage to care so that immediate linkage to care becomes the standard across the United States, allowing people to begin receiving care and treatment within hours or days of their diagnosis no matter where they live. This effort may require that some clinics and health departments work to reduce facility-based, government-based, workforce, or administrative barriers to initiating care and treatment. Red carpet and warm-handoff programs provide low-barrier access by linking newly diagnosed people to care and treatment services, often within the same day.[112, 113] For example, these programs, which often integrate robust navigation services, may schedule medical appointments on behalf of the patient, drive newly diagnosed people who lack transportation from an HIV testing site to a trusted clinic, or help people who need assistance complete required forms and paperwork.

Strategies

2.1.1 Provide same-day or rapid (within 7 days) start of antiretroviral therapy for persons who are able to take it; increase linkage to HIV health care within 30 days for all persons who test positive for HIV.

2.1.2 Increase the number of schools providing on-site sexual health services through school-based health centers and school nurses, and linkages to HIV testing and medical care through youth-friendly providers in the community.

Objective 2.2 Identify, engage, or reengage people with HIV who are not in care or not virally suppressed

Although improvements have been made over time, only 58% of people with diagnosed HIV were retained in care in 2019[2] and 81% of people with diagnosed HIV were rapidly linked to care within 1 month of diagnosis. In addition, 23% of people with HIV who are not receiving care account for 43% of new infections.[28] This population often needs highly tailored approaches to identify, conduct outreach, ascertain barriers to care, and create individualized care plans to facilitate entry into care, followed by navigation and other services to support retention in care, such as short- or long-term housing assistance, benefits counseling across the social services spectrum, and employment counseling. New solutions must be identified to engage and reengage populations that, to date, systems have been unsuccessful in reaching and retaining in care. Feedback and evaluations of services from people with HIV are critical to understanding and improving how services are received by those who need them the most. Attention should also be paid to eligibility and other requirements placed on people seeking care such as eligibility processes and duplicative paperwork requests.

Data-to-care models based on solid, interwoven data points, and other evidence-based interventions focused on finding people not in care and people who are not yet virally suppressed, are proven strategies to reengage people over the long term.[114] Disparate data systems must first be linked to identify people who have tested HIV positive but do not have recent indicators of quality care, people who have fallen out of care, people in care who lack timely prescription refills, and people in care who have not achieved or maintained viral suppression. Entering into formal data sharing agreements ensures that the uses of the data, responsibilities, and protections are clearly delineated for all parties. Such agreements are needed among state public health surveillance systems, state and local health departments, tribes, tribal organizations, urban Indian organizations, the RWHAP, federally funded health centers of all types, community-based organizations, STI specialty clinics, HOPWA programs, Medicaid, Departments of Corrections, pharmacies and pharmacy benefits managers, and other components of the health system serving people with HIV in a geographic area. A goal of data sharing agreements is to reduce administrative burden on providers as well as individuals, thereby avoiding redundant intakes, increasing efficiency, and preparing providers to work alongside clients to develop comprehensive treatment plans without delay.

Strategies

2.2.1 Expand uptake of data-to-care models using data sharing agreements, integration and use of surveillance, clinical services, pharmacy, and social/support services data to identify and engage people not in care or not virally suppressed.

2.2.2 Identify and address barriers for people who have never engaged in care or who have fallen out of care.

Objective 2.3 Increase retention in care and adherence to HIV treatment to achieve and maintain long-term viral suppression and provide integrative HIV services for HIV-associated comorbidities, coinfections, and complications, including STIs

People with HIV need ongoing support to stay in care and adhere to ART to achieve and maintain viral suppression.[115] Approaches to increase retention in care include higher levels of personal contact with a patient navigator or community health worker to ensure care receipt; reminders about appointments and calls to discuss why appointments were missed; patient navigation services designed to help patients identify, apply for, and receive necessary services to bolster medical care; medical case management; financial incentives; and low-threshold care including walk-in appointments and on-site pharmacies.[116, 117] Among adherence interventions are those designed to ensure the efficiency of receiving and taking medications such as 90-day prescriptions, options for medication pick-up or receipt by mail, use of technology such as medication reminder apps, and adherence counseling. Other interventions must address common barriers to adherence and retention, such as providing co-located treatment for HIV and mental health and substance use disorders.

Ongoing research in a variety of disciplines is also needed to improve care retention, medication adherence, and sustained viral suppression. Research topics include next-generation therapeutics that are longer-acting, less toxic, and have fewer side effects and complications, as well as behavioral and social sciences to better understand and address barriers to treatment uptake and adherence, as well as disparities. Biomedical, behavioral, and implementation research approaches can be combined to increase viral suppression, reduce HIV transmission, and improve health for all affected populations. Basic, translational, and clinical research can increase understanding of HIV-related comorbidities, coinfections, and complications, which can interfere with retention, adherence, or viral suppression.

New and differentiated models of care, especially those that integrate HIV prevention, care, and supportive services, alongside broader structural interventions, must be tailored and implemented for priority populations. Many populations such as youth transitioning from pediatric to adult care, people without consistent and stable housing, and people released from correctional facilities need well-coordinated interventions that span systems, providers, and payers and address structural, medical, behavioral, and support service concerns.

Strategies

2.3.1 Support the transition of health care systems, organizations, and patients/clients to become more health literate in the provision of HIV prevention, care, and treatment services.

2.3.2 Develop and implement effective, evidence-based or evidence-informed interventions and supportive services that improve retention in care.

2.3.3 Expand implementation research to successfully adapt effective evidence-based interventions, such as HIV telehealth, patient and peer navigators, accessible pharmacy services, community health workers, and others, to local environments to facilitate uptake and retention to priority populations.

2.3.4 Support ongoing clinical, behavioral, and other research to support retention in care, medication adherence, and durable viral suppression.

Objective 2.4 Increase the capacity of the public health, health care delivery systems, and health care workforce to effectively identify, diagnose, and provide holistic care and treatment for people with HIV

Increasing viral suppression requires expanded capacity of public health, health care and support service delivery systems, and the health workforce to be flexible and responsive to the needs of people with HIV. COVID-19 has strained HIV care and prevention systems and has highlighted gaps within our nation's response. Federal and state programs focused on HIV should work to identify opportunities to expand the HIV workforce, including partnerships with medical colleges, particularly Historically Black Colleges and Universities, and incentives for clinicians to provide HIV and related services. Increasing the diversity of providers offering HIV prevention and care services is one important capacity-building approach. In addition, publicly funded organizations can increase the diversity of their workforce and provide training to ensure culturally competent care and knowledge of best practices for caring for people from diverse backgrounds.[118] Health care and support systems can also take advantage of different types of health professionals such as nurses, advanced practice providers, pharmacists, and behavioral health specialists to ensure that any workforce shortages can be addressed. Innovative staffing models can also build capacity to better meet the needs of people with HIV including the use of community health workers, linkage to care and reengagement specialist teams, task sharing, integrated care teams, and use of peer mentors.[119] Organizations should also work to ensure that their staff represents the populations served, including hiring pathways for people with HIV and providing opportunities for leadership and leadership development. In addition, sustained continuous quality improvement programs must be utilized to ensure that up-to-date and high-quality care is being provided by integrated and diverse care teams.

In addition to the RWHAP, patient-centered medical homes and health homes create opportunities to address medical and support service needs of people with HIV through coordinated, team-based, and accessible programs including co-location of mental health, substance use, geriatric, reproductive, and other related health care services. Similar to HIV prevention, expanding care and treatment capacity must also include delivery of additional resources, incentives, training, and technical assistance to existing systems as well as development of new systems in areas with limited availability. For example, establishing new partnerships and advancing telehealth arrangements to expand access to professionals with specialized backgrounds should be explored to increase access to services in geographically underserved areas, as well as expanding broadband access, so that those in underserved and rural areas may have equitable access to telehealth arrangements. The design of programs to reach and engage people out of care, people never in care, and people who are challenged to stay in care may require novel approaches, services, and partnerships to address issues of trauma, poverty, and associated conditions that are obstacles to care. The creation and implementation of new programs should involve input and feedback from people with HIV because they have unique knowledge to share. Systems should also offer low-threshold capacity-building resources to organizations and retail health clinics led and staffed by local members of the priority populations to enhance their ability to apply for and receive grants and foundation funds to increase the number of services being provided in and by affected communities.

In addition, to address the unique needs of people aging with HIV and long-term survivors, federal and state programs and community-based organizations must conduct analyses to identify gaps in service delivery for this population so that programs can be implemented to address shortfalls. This analysis should include federal programs such as Medicare and the RWHAP to ensure adequacy of care and support services, benefits, and policies.

Strategies

2.4.1 Provide resources, value-based and other incentives, training, and technical assistance to expand workforce and systems capacity to provide or link clients to culturally competent and linguistically appropriate care, treatment, and supportive services especially in areas with shortages that are geographic, population, or facility based.

2.4.2 Increase the diversity of the workforce of providers who deliver HIV care and supportive services.

2.4.3 Increase inclusion of paraprofessionals on teams by advancing training, certification, supervision, reimbursement, and team functioning to assist with screening/management of HIV, STIs, viral hepatitis, and mental and substance use disorders and other behavioral health conditions.

Objective 2.5: Expand capacity to provide whole-person care to older adults with HIV and long-term survivors

More than one-half (52%) of people in the United States with diagnosed HIV were aged 50 and older in 2019.[3] Of the more than 500,000 clients served by the RWHAP in 2019, 46.8% were aged 50 years and older—an increase from 31.6% in 2010. Of clients aged 50 years and older receiving RWHAP HIV medical care, 90.9% were virally suppressed, which was slightly higher than the national RWHAP average (88.1%).[120] The proportion of older adults with HIV is expected to continue to rise because of the effectiveness of ART, as well as new diagnoses within this age group, which accounts for approximately 17% of all diagnosed HIV in the United States.

People aging with HIV, many of whom are long-term survivors, have unique mental health and physical health needs.[121] Although people with HIV over age 50 have the highest viral suppression rates and the lowest incidence rates of any age group, the effects of aging, chronic inflammation, frailty, and distinctive behavioral health issues can compound the care and support service needs for this population.

Although modern antiretroviral therapies increase the life expectancy of people living with HIV, many challenges and opportunities for the treatment of HIV and HIV-associated comorbidities, coinfections, and complications across the lifespan persist. Even when long-term viral suppression is achieved, people living with HIV over age 50 are more likely than their peers without HIV to experience age-related complications such as cardiovascular disease, lung disease, infection-related and non-infection-related cancers, neurocognitive and neuropsychiatric disorders, osteopenia/osteoporosis, liver cirrhosis, and renal disease. In addition, people living with HIV infection may suffer from multiple morbidities, polypharmacy, declining physical and cognitive function, alterations in body composition, social isolation, and increased caregiver burden.

Older adults with HIV and long-term survivors of HIV often experience social isolation, loneliness, and a lack of social support, as well as HIV- and age-related stigma. These issues may prevent them from seeking or staying in care and can contribute to poor mental and physical health. The U.S. HIV care and treatment system must adapt to ensure that people aging with HIV can receive whole-person care that addresses their HIV- and aging-related health needs, along with support services such as mental health, transportation, housing, food and nutrition, and benefits counseling, among many others. Relatedly, our nation's programs designed to serve older adults—including Medicare, Medicaid, and programs supported through the HHS Administration for Community Living including

State Units on Aging, Area Agencies on Aging, and other community-based organizations and social service providers—must be prepared to meet the needs of people with HIV. Partnerships between HIV care providers and community-based organizations can greatly enhance the ability of people aging with HIV to maintain independence and experience improved quality of life (see Box 8 for a discussion of HIV Prevention and Care Across the Lifespan).

Strategies

2.5.1 Identify, implement, and evaluate models of care that meet the needs of people with HIV who are aging and ensure quality of care across services.

2.5.2 Identify and implement best practices related to addressing psychosocial and behavioral health needs of older people with HIV and long-term survivors including substance use treatment, mental health treatment, and programs designed to decrease social isolation.

2.5.3 Increase HIV awareness, capability, and collaboration of service providers to support older people with HIV, including in settings such as aging services, housing for older adults, substance use treatment, and disability and other medical services.

2.5.4 Promote research, cross-agency collaborations and sharing of research discoveries that address specific aging-related conditions in people with HIV, and other comorbidities and coinfections that can impact people with HIV of all ages.

2.5.5 Develop and optimize collaborative multi-agency and multi-sectoral approaches and strategies to address emergent and evolving challenges facing people living with HIV at various life stages to support healthy aging with HIV.

Objective 2.6: Advance the development of next-generation HIV therapies and accelerate research for HIV cure

Research and programmatic implementation of varied HIV therapeutic modalities that meet the needs of diverse communities of people with HIV is critical to reduce onward transmission and to achieve complete virus remission, eradication, and HIV cure. Collaboration must exist on a global scale, as much of the research on these new therapies is being done in highest incidence settings.

Novel ART classes and drugs that target the HIV lifecycle are in various stages of preclinical and clinical development and are under investigation in clinical trials. Next-generation therapeutics research includes basic and clinical studies to optimize efficient delivery of therapies and interventions that address drug toxicity, viral resistance, adherence, and retention in care and stigma associated with ART use.

Numerous novel diagnostic and delivery systems are similarly being developed and tested, including subcutaneous, intravenous, topical, implantable, and long-acting oral formulations. New delivery systems and technologies will improve adherence to drug regimens and reduce the burden on health systems.

Research toward safer, effective, and long-lasting therapeutics that successfully achieve viremic control in the absence of ART or completely eradicate the HIV infection (cure) must continue, and must seek a better understanding of the viral reservoir dynamics, persistent viral replication consequences, and the host immune system clearance capacity to remove residual infection.

In parallel to research efforts, safe, long-acting, more efficacious regimes must be rapidly approved and implemented to meet the needs of communities of people with HIV. Achieving these goals will benefit from robust public-private partnerships both in basic and clinical research as well as in implementation planning and delivery to ensure community involvement and advocacy.

Strategies

2.6.1 Promote research and encourage public-private partnerships to accelerate new therapies to achieve sustained viral suppression and to address drug toxicity, viral resistance, adherence, and retention in care and stigma associated with ART use.

2.6.2 Increase investment in innovative basic and clinical research to inform and accelerate a research agenda to discover how to sustain viral suppression, achieve ART-free remission, reduce and eliminate viral reservoirs, and achieve HIV cure.

INDICATORS OF PROGRESS

Working together to pursue these objectives, the nation can achieve the following targets by 2025:

Indicator 5 Increase linkage to care within 1 month of diagnosis to 95% from a 2017 baseline of 77.8%.

Indicator 6 Increase viral suppression among people with diagnosed HIV to 95% from a 2017 baseline of 63.1%.

GOAL 3: REDUCE HIV-RELATED DISPARITIES AND HEALTH INEQUITIES

THE OPPORTUNITY

Advances in HIV prevention, testing, care, treatment, and supportive services have led to significant declines in new HIV transmissions and deaths. They also make it possible for the nation to envision ending the HIV epidemic. However, realizing this vision requires that every person across the United States with or who experiences risk for HIV has access to high-quality and culturally competent prevention, diagnostic, care, treatment, and supportive services that are non-stigmatizing, non-discriminatory, inclusive, and responsive to their needs. Further, issues such as discrimination and systemic racism that contribute to differences in the quality of and access to health care and other necessities such as housing and behavioral and substance use services, and lead to ongoing disparities among racial, ethnic, and sexual and gender minority populations, must be addressed.

The Strategy recognizes racism as a serious public health threat that directly affects the well-being of millions of Americans. Racism is not only the discrimination against one group based on the color of their skin or their race or ethnicity, but also the structural barriers that impact racial and ethnic groups differently to influence where a person lives, where they work, where they play, and where they gather as a community. Over generations, these structural inequities have resulted in racial and ethnic health disparities that are severe, far-reaching, and unacceptable.[122] Across the country, federal, state, and local leaders are declaring racism to be a public health crisis, an important step in the movement toward equity.[120] This recognition comes with the need for a more equitable HIV response that focuses on populations with the greatest need.

Reducing these disparities entails focusing on the needs of disproportionately affected populations, supporting racial justice, combating HIV-related stigma and discrimination, providing leadership and employment opportunities for people with or who experience risk for HIV, and addressing social determinants of health and co-occurring conditions to reduce health inequities and disparities. Therefore, the Strategy fully recognizes that the national HIV goals can only be achieved through collaborative efforts at the federal, state, tribal, territorial, and local levels that focus on reducing HIV-related disparities and by ongoing commitment to understand and address the central factors that create HIV inequities.

In recent years, the nation and individual states have made progress in the area of HIV-related disparities. For example:

- **The RWHAP significantly reduced viral suppression disparities among client populations**, particularly women, transgender people, youth, Blacks, and people with unstable housing. Overall, 88% of clients receiving medical care in the RWHAP were virally suppressed in 2019.[5] From 2010 to 2019, the gap between male and female clients decreased from nearly 5 percentage points to <1 percentage point. In addition, the gap between male and transgender clients decreased from 9 percentage points to 5 percentage points. Similarly, the disparity between viral suppression rates in Black clients and White clients was 13 percentage points in 2010 but 7 percentage points in 2019.[5, 6] HRSA and its RWHAP recipients have continued to use these data to drive programs and decision-making.
- **Disparities in rates of new infections declined in some populations.** From 2015 to 2019 the United States saw reductions of disparities in the rates of new HIV infections among gay and bisexual men, Black gay and bisexual men, and Black women.[11]
- **Since 2014, at least nine states (CA, CO, IA, IL, MI, MO, NV, NC, VA) have modernized or repealed their HIV criminal exposure laws.** Changes have included removing HIV prevention issues from the criminal code and including them instead under disease control regulations, requiring intent to transmit or actual HIV transmission, or providing for defenses for taking measures to prevent transmission.

CHALLENGES

The following challenges hinder efforts to reduce HIV-related disparities and health inequities:

- Disparities in HIV prevalence persist.[124]
- The South bears a disproportionate HIV burden.
- Disparities are also evident in the proportion of people with HIV with viral suppression.[2]
- Significant disparities exist in PrEP uptake by age, race, sex at birth, and geographic location.[11, 63, 64]

Research to better understand and address such disparities and inequalities—including through community-based participatory research methods—can help improve HIV testing and engagement and retention in prevention and care services and can enhance the health and well-being of people with or who experience risk for HIV in underserved and marginalized communities.

Also important is consideration of and appropriate and proportional response to HIV among groups that represent a small share of both the population and of HIV infections. Although it is vital to focus national efforts in communities with the highest burden, HIV prevention, care, and treatment must continue to be supported in localities with concentrations of groups such as Asian Americans and Pacific Islanders and American Indians/Alaska Natives, and informed by the best available data.

A Focus on Health Inequities

Certain racial and ethnic minority groups have higher rates of HIV incidence, prevalence, poor health outcomes (lower viral suppression), and mortality, compared to non-Hispanic Whites.[125] Health disparities can stem from inequities in the social determinants of health and highlight the need to focus on not only HIV prevention and care efforts, but also how programs, practices, and policies affect racial and ethnic minority communities. Persons from racial and ethnic minority groups are more likely to be uninsured compared to non-Hispanic Whites,[126] limiting their access to health care. Sexual and gender minorities also face health inequities. Sexual and gender minorities have lower levels of health insurance and access to regular health care compared to their heterosexual counterparts.[37, 38] Barriers to health care access include lack of transportation and childcare, inability to take time off from work, communication and language barriers, racism, discrimination, and lack of trust in health care providers.[127] Further, CDC's 2019 Youth Risk Behavior Survey data show that substantial health disparities exist among an estimated 2.6 million sexual minority students, placing them at risk for negative health outcomes, including HIV infection.

The Strategy recognizes the importance of addressing social determinants of health to improve health outcomes for racial, ethnic, and sexual and gender minority groups. By working to establish policies and programs that positively

GOAL 3: REDUCE HIV-RELATED DISPARITIES AND HEALTH INEQUITIES

Objectives

3.1 Reduce HIV-related stigma and discrimination

3.2 Reduce disparities in new HIV infections, in knowledge of status, and along the HIV care continuum

3.3 Engage, employ, and provide public leadership opportunities at all levels for people with or who experience risk for HIV

3.4 Address social and structural determinants of health and co-occurring conditions that impede access to HIV services and exacerbate HIV-related disparities

3.5 Train and expand a diverse HIV workforce by further developing and promoting opportunities to support the next generation of HIV providers including health care workers, researchers, and community partners, particularly from underrepresented populations

3.6 Advance HIV-related communications to achieve improved messaging and uptake, as well as to address misinformation and health care mistrust influence social and economic conditions and by supporting changes in individual behavior, health can be improved and sustained, and disparities reduced. Improving the conditions in which we live, learn, work, play, age, and worship and the quality of our relationships will create a healthier population, society, and workforce.[128] Application of a "health in all policies" strategy, a cross-sector collaborative approach to integrating health into policies and programs to close the health gaps,[129-130] can be implemented across all areas and levels of government and in the community to foster achievement of these aims.

SUMMARY OF OBJECTIVES

The following objectives are critical to reducing HIV-related disparities and health inequities:

3.1 Reduce HIV-related stigma and discrimination

3.2 Reduce disparities in new HIV infections, in knowledge of status, and along the HIV care continuum

3.3 Engage, employ, and provide public leadership opportunities at all levels for people with or who experience risk for HIV

3.4 Address social and structural determinants of health and co-occurring conditions that impede access to HIV services and exacerbate HIV-related disparities

3.5 Train and expand a diverse HIV workforce by further developing and promoting opportunities to support the next generation of HIV providers including healthcare workers, researchers, and community partners, particularly from underrepresented populations

3.6 Advance HIV-related communications to achieve improved messaging and uptake, as well as to address misinformation and health care mistrust

OBJECTIVES AND STRATEGIES

Objective 3.1 Reduce HIV-related stigma and discrimination

Many people with HIV experience stigma and discrimination because of their HIV status. Stigma is an attitude of disapproval and discontent toward a person or group because of the presence of an attribute perceived as undesirable. Discrimination is often a consequence of stigma, occurring when unfair and often unlawful actions are taken against people based on their belonging to a particular stigmatized group. HIV stigma and discrimination can pose complex barriers for people with or who experience risk for HIV, preventing them from seeking prevention tools, learning their HIV status, and accessing medical care, treatment, and supportive services. Interested parties and organizations from all sectors of society, including government, faith communities, businesses, schools, and others, must work to combat stigma and discrimination in order to reduce new transmissions and improve health outcomes for people with HIV.

Ending the HIV epidemic requires addressing structural barriers to HIV prevention and care. HIV-specific criminal laws perpetuate HIV-related stigma, and discrimination can also deter individuals from getting tested. Some of these laws criminalize behavior that pose low or no risk for transmitting HIV and apply regardless of actual HIV transmission. These outdated laws do not reflect our current understanding of HIV and should be repealed or updated. At least nine states have done so since 2014. Such efforts must ensure that criminal laws and policies regarding HIV transmission are based on the latest scientific evidence and reflect effective public health strategies, and that legislators, prosecutors, and law enforcement officials have an accurate understanding of HIV transmission risks (see Box 7).

Discriminatory practices cause stress and play a role in the health outcomes of minorities.[131] Public health and health care systems should be respectful of and responsive to the health beliefs, practices, accessibility needs, and cultural and language needs of diverse patients.[132] At the community level, interested parties and advocates should be equipped with knowledge and tools to address misconceptions and change norms that are associated with HIV-related stigma and discrimination. At the individual level, multiple approaches to address interpersonal and internalized stigma should be available to people with or who experience risk for HIV as well as their family, friends, health care providers, and others.

HIV-related stigma and discrimination and their effects on people with or who experience risk for HIV should not be viewed in a silo. Stigma and discrimination come in different forms and are often complicated when people also experience stigma and discrimination related to—among other identities or experiences—race and ethnicity, sexual orientation or sexual behavior, other STIs, gender identity, substance use, mental health, homelessness, socioeconomic circumstance, justice involvement, immigration status, age, disability, or sex work.[108, 133] Additional research, innovative solutions, and replication of global efforts, such as those from the President's Emergency Program for Emergency AIDS Relief (PEPFAR), to address the drivers, facilitators, and manifestations of stigma are needed.[134] These solutions should be integrated into the delivery of services that are responsive and sensitive to the unique needs of populations that face intersectional stigmas and intersectional discrimination.

Strategies

3.1.1 Strengthen enforcement of civil rights laws (including language access services and disability rights), promote reform of state HIV criminalization laws, and assist states in protecting people with HIV from violence, retaliation, and discrimination associated with HIV status, homophobia, transphobia, xenophobia, racism, substance use, and sexism.

3.1.2 Ensure that health care professionals and front-line staff complete education and training on stigma, discrimination, and unrecognized bias toward populations with or who experience risk for HIV, including LGBTQI+ people, immigrants, people who use drugs, and people involved in sex work.

3.1.3 Support communities in efforts to address misconceptions and reduce HIV-related stigma and other stigmas that negatively affect HIV outcomes.

3.1.4 Ensure resources are focused on the communities and populations where the need is greatest, especially Black, Latino, and American Indian/Alaska Native and other people of color, particularly those who are also gay and bisexual men, transgender people, people who use substances, sex workers, and immigrants.

3.1.5 Create funding opportunities that specifically address social and structural drivers of health as they relate to Black, Latino, and American Indian/Alaska Native and other people of color.

BOX 7
STATE HIV CRIMINALIZATION LAWS

During the early years of the HIV epidemic, many states implemented HIV-specific criminal exposure laws to discourage behavior that they believed might lead to transmission, promote safer sex practices, and, in some cases, receive funds to support HIV prevention activities. These laws were passed at a time when very little was known about HIV, including how it was transmitted and how best to prevent or treat it. For example, many were enacted before the advent of pre-exposure prophylaxis (PrEP), which reduces the risk of acquiring HIV sexually by 99% when taken daily, or the availability of antiretroviral therapy (ART), which—when taken as prescribed—helps an individual with HIV achieve and maintain a suppressed viral load so that they have effectively no risk of transmitting HIV to sexual partners. As such, many of these state laws criminalize behavior that cannot transmit HIV and apply regardless of actual transmission.

BOX 7
STATE HIV CRIMINALIZATION LAWS *(CONTINUED)*

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 sex work. In 2021, CDC assessed state laws and grouped them into four categories:

1. HIV-specific laws that criminalize or control behaviors that can potentially expose another person to HIV.
2. STI, communicable, contagious, infectious disease laws that criminalize or control behaviors that can potentially expose another person to STIs/communicable/infectious disease, perhaps including HIV.
3. Sentence enhancement laws specific to HIV or STI that do not criminalize a behavior but increase the sentence length when a person with HIV commits certain crimes.
4. No specific criminalization laws.

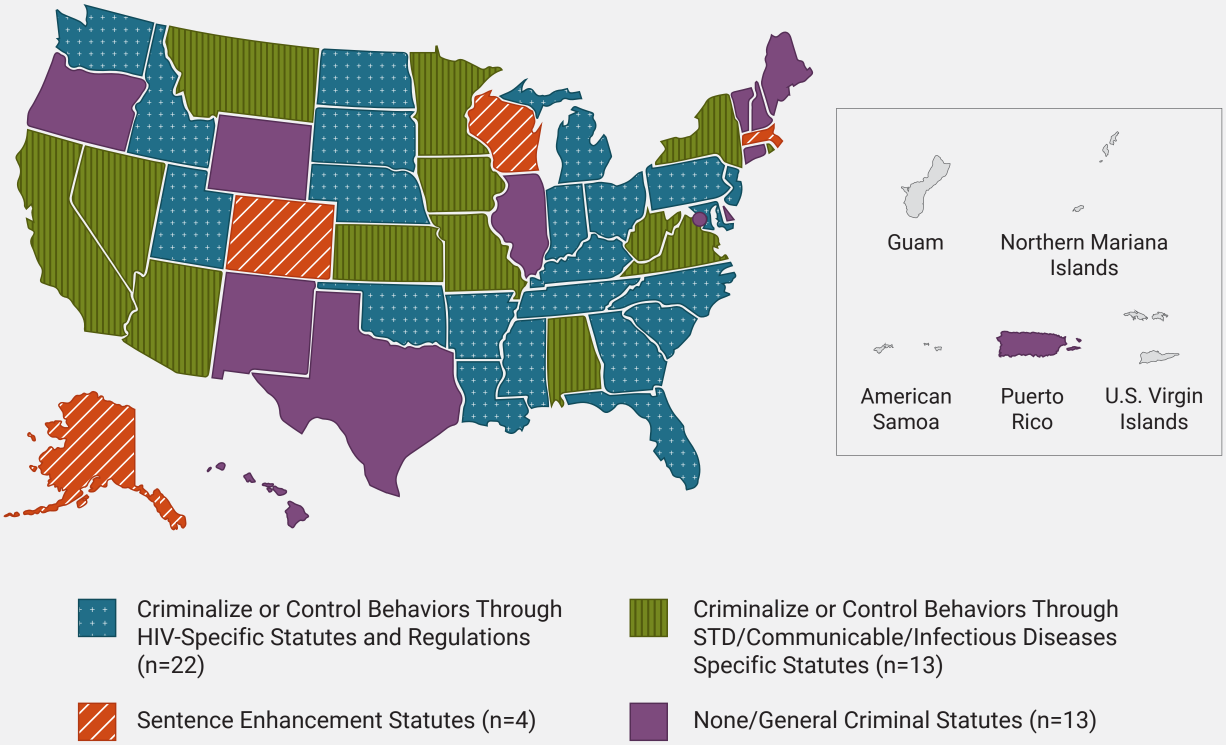


Figure 9. State criminal HIV exposure laws, as of 2021

As shown in Figure 9, these laws vary as to what behaviors are criminalized or what behaviors result in additional penalties. Several states criminalize one or more behaviors that pose a low or negligible risk for HIV transmission. Only 9 of the 35 states with HIV criminalization laws account for HIV prevention measures that reduce transmission risk, such as condom use and ART.

BOX 7
STATE HIV CRIMINALIZATION LAWS *(CONTINUED)*

Since 2014, at least nine states have modernized or repealed their HIV criminal laws: California, Colorado, Illinois, Iowa, Michigan, Missouri, Nevada, North Carolina, and Virginia. Changes have included removing HIV prevention issues from the criminal code and including them under disease control regulations, requiring intent to transmit or actual HIV transmission, or providing defenses for taking measures to prevent transmission such as viral suppression or being noninfectious, condom use, and partner PrEP use.

After more than 30 years of HIV research and significant biomedical advancements to treat and prevent HIV transmission, many state laws are still outdated and do not reflect our current understanding of HIV. In many cases, this same standard is not applied to other treatable diseases. Further, these laws have not increased disclosure and may discourage HIV testing, increase stigma against people with HIV, and exacerbate disparities. To end the HIV epidemic, public health, criminal justice, and legislative systems must work together to ensure that laws protect the community, are evidence-based and just, and support public health efforts. When a law meant to protect the public is not working as intended, is unjust, and may be hurting efforts to keep communities healthy, common solutions must be found to better meet public health and public safety goals. States should repeal or update these outdated laws and practices.

Source: CDC[135, 136]

Objective 3.2 Reduce disparities in new HIV infections, in knowledge of status, and along the HIV care continuum

Monitoring of progress toward HIV targets should identify, raise awareness of, and inform appropriately tailored interventions to respond to ongoing and emerging disparities among various populations and in geographic areas. With improved mechanisms to measure, monitor, and report data in a timely manner and enhanced quality, accessibility, sharing, and use of data (see Goal 4), governments and organizations can more quickly identify disparities and direct resources appropriately.

When disparities are identified, tailored interventions must be developed in partnership with the affected populations. Specific populations may have unique or specialized needs and face challenges that require more tailored approaches based on sociodemographic, geographic, cultural, and other characteristics that may be associated with HIV risk or health-promoting behaviors.

Strategies

3.2.1 Increase awareness of HIV-related disparities through data collection, analysis, and dissemination of findings.

3.2.2 Develop new and scale up effective, evidence-based or evidence-informed interventions to improve health outcomes among priority populations and other populations or geographic areas experiencing disparities.

Objective 3.3 Engage, employ, and provide public leadership opportunities at all levels for people with or who experience risk for HIV

Achieving the goals of this Strategy and ending the HIV epidemic demand a whole-of-society effort that must include and elevate the diverse voices and experiences of people with or who experience risk for HIV, as well as their partners, families, and communities. Jurisdictions and organizations must meaningfully engage and employ people with or who experience risk for HIV in the development, implementation, monitoring, and assessment of policies, programs, and services. This includes creating opportunities for employment and advancement, as well as fair compensation, wherever possible, particularly for individuals from the priority populations identified in this Strategy. Their experiences and expertise can inform efforts to remove barriers that hinder access to needed information or services and to design services that meet unique needs as well as enhance cultural competency. Governments and other institutions working to meaningfully engage people with or who experience risk for HIV must develop partnerships with networks of people with or who experience risk for HIV and other organizations that engage and serve populations most affected by HIV in each community, thereby identifying ways to optimize messages and services and to combat stigma and discrimination. This includes meaningful engagement of Black, Latinx, American Indian/Alaska Native, and other people of color communities—especially people with or experiencing risk for HIV, people who inject drugs, people with a history of justice involvement, immigrants, sex workers, transgender people, and gay and bisexual men—in HIV planning, service delivery, program monitoring/assessment, research, and policymaking.

Strategies

3.3.1 Create and promote public leadership opportunities for people with or who experience risk for HIV.

3.3.2 Work with communities to reframe HIV services and HIV-related messaging so that they do not stigmatize people or behaviors.

Objective 3.4 Address social and structural determinants of health and co-occurring conditions that impede access to HIV services and exacerbate HIV-related disparities

Addressing social determinants of health and co-occurring conditions, such as noncommunicable comorbidities and coinfections, is essential to reducing HIV-related health disparities and inequities. For many people with or who experience risk for HIV, addressing basic and immediate needs, such as safety and/or shelter, takes precedence over HIV testing, prevention, care, or treatment. Lack of continuous health insurance coverage, inability to pay for care and treatment, inadequate housing, food insecurity, under- and unemployment, medical mistrust, provider misconceptions and bias, low health literacy, language barriers, and involvement in the justice system all act as barriers to improved HIV outcomes.

In other cases, people may be interested in HIV services, but shortages of a skilled and competent workforce or lack of nearby HIV services hinder their ability to access them. These limitations are made worse by inadequate infrastructure, including limited or no broadband internet services and lack of public transportation.[94] Structural barriers such as laws or policies can also impede the availability of or access to HIV services. For example, support for the legalization or expansion of SSPs is needed in many jurisdictions, particularly in areas with a significant population of people who inject drugs.

Ending the HIV epidemic requires recognition of the need for interventions and pooled resources to address upstream factors often rooted in racism and other social and structural barriers.[137] Programs could destigmatize HIV services, increase service utilization, address social determinants of health, and improve health outcomes by integrating them in multi-disease, community-based testing, care, and treatment models.[138] Ultimately, the success of biomedical and behavioral interventions may be directly impacted by whether structural interventions are effectively integrated to support them. Such integration supports person-centered care that considers all of the patient's needs and lived experiences, including those separate from HIV that vary across the lifespan (see Box 8). Integration also includes establishing additional opportunities to engage in partnerships that make it possible to address clients' unmet needs, maximize reach, and promote efficiency and sustainability.

BOX 8
ADDRESSING HIV PREVENTION AND CARE ACROSS THE LIFESPAN

Responsive services that recognize and support variable and episodic needs across the lifespan are necessary to best support people with or who experience risk for HIV.

Much progress has been achieved in preventing perinatal transmission of HIV in the United States; only 65 HIV infections were attributed to perinatal transmission in 2018.[139] Although rare, perinatal transmission of HIV still occurs in the United States but disproportionately impacts Black children.[139] Limited antiretroviral therapy (ART) formulations for infants and children make HIV management in these age groups challenging. Questions remain about the impact of HIV and ART exposure in utero, as well as HIV infection and long-term ART on the growing and developing child. While early treatment reduces morbidity and mortality from HIV, whether very early ART can ameliorate complications of HIV and preserve neurodevelopment, optimal cognitive functioning, and mental health in children with HIV is unclear. Preventing mother-to-child transmission requires intensive case management and coordination across many systems and payors.

Youth experience worse HIV outcomes on status awareness, pre-exposure prophylaxis uptake, and health outcomes. Children and young adults with HIV need tailored and often more intensive medical and support services to support them as they grow and become young adults. Schools play an important role in the primary prevention of HIV in youth by offering comprehensive sexual health education and on-site sexual health services through school-based health centers and school nurses, or in collaboration with community partners that provide services, such as periodic, school-wide HIV and STI screening events or mobile clinics. Schools that cannot provide direct sexual health services can establish integrated referral systems that link students to youth-friendly providers in the community. There is a need for both primary prevention approaches and HIV care models that are tailored to groups of youth at disproportionate risk of HIV, including young gay, bisexual, and other men who have sex with men and people who inject drugs.

Across the lifespan, individuals with HIV will also experience a spectrum of non-HIV-specific needs, which may require coordination across various health and social services systems, such as sexual and reproductive health or transition-related care for transgender individuals, in order to ensure affirming whole-person care.

Similarly, tailored approaches are required to meet the HIV prevention, testing, and care needs of older adults. Older Americans are more likely than younger Americans to be diagnosed with HIV infection late in the course of their disease, meaning they get a late start to treatment and possibly experience more damage to their immune system. Thanks to effective HIV care and treatment, people with HIV who are diagnosed early in their infection, and who get and stay on ART, can keep the virus suppressed and live long and healthy lives. Therefore, the number of older adults with HIV is growing; more than one-half of people with diagnosed HIV in the United States were aged 50 and older in 2018.[125]

Older people with HIV, especially long-term survivors, face different health and psychosocial issues than their younger counterparts and thus require appropriately tailored HIV care and treatment services. These unique needs include screening for, assessment of, and treatment of HIV-associated, non-AIDS conditions as well as age-associated diseases for which people with HIV experience increased risk, and addressing social challenges such as social isolation or depression faced by many people aging with HIV and especially those who are long-term survivors of the disease. As this population continues to age, it will be necessary to research, develop, and implement effective interventions, and adapt and appropriately fund systems of care, with attention to comorbidities related to aging.

BOX 8
ADDRESSING HIV PREVENTION AND CARE ACROSS THE LIFESPAN *(CONTINUED)*

HIV systems of care must incorporate and form partnerships with service providers for older adults, including local Area Agencies on Aging and housing for older adults, to ensure that older people with HIV can also access social services as well as qualified mental health and substance use services that are provided by people experienced in elder care and HIV. Ensuring that agencies focused on elder services can provide age-friendly, affirming care to LGBTQI+ individuals and those with HIV is imperative as the population in need of those services continues to grow.

There is a clear need for both primary prevention approaches and HIV care models tailored to different life stages. Cross-agency efforts are needed to develop, adapt, and implement treatments and interventions specific for the different life stages in order to improve and sustain HIV health outcomes.

Sources: Mandsager et al.[6], McNeil and Rowe[140]

Strategies

3.4.1 Develop whole-person systems of care and wellness that address co-occurring conditions for people with or who experience risk for HIV.

3.4.2 Adopt policies and laws that reduce cost, payment, coverage, and/or access barriers to improve the delivery and receipt of services for people with or who experience risk for HIV.

3.4.3 Improve screening and linkage to services for people with or who experience risk for HIV who are diagnosed with and/or are receiving services for co-occurring conditions.

3.4.4 Develop and implement effective, evidence-based and evidence-informed interventions that address social and structural determinants of health among people with or who experience risk for HIV including lack of continuous health care coverage, HIV-related stigma and discrimination in public health and health care systems, medical mistrust, inadequate housing and transportation, food insecurity, unemployment, low health literacy, and involvement with the justice system.

3.4.5 Increase the number of schools that have implemented LGBTQ-supportive policies and practices, including (1) having a Gay/Straight Alliance (GSA), Gender Sexuality Alliance, or similar clubs, (2) identifying safe spaces, (3) adopting policies expressly prohibiting discrimination and harassment based on sexual orientation or gender identity, (4) encouraging staff to attend professional development, (5) facilitating access to out-of-school health service providers, (6) facilitating access to out-of-school social and psychological service providers, and (7) providing LGBTQ-relevant curricula or supplementary materials.

3.4.6 Develop new and scale up effective, evidence-based or evidence-informed interventions that address intersecting factors of HIV, homelessness or housing instability, mental health and violence, substance use, and gender especially among cis- and transgender women and gay and bisexual men.

Objective 3.5: Train and expand a diverse HIV workforce by further developing and promoting opportunities to support the next generation of HIV providers including healthcare workers, researchers, and community partners, particularly from underrepresented populations

Continuous building of a diverse HIV workforce is critical to achieve HIV epidemic control. Supporting and promoting equity and diversity is fundamentally important to adequately and effectively advance research and enhance innovation. Diversity, inclusion, and community representation are key to achieving creative problem-solving perspectives, and to ensuring the comprehensive cultural spectrum necessary to understand epidemic dynamics.

Multiple obstacles, including the lack of opportunity for minority institutions and communities, paucity of adequate mentorship, and resource limitations, impede achieving equity and diversity in the health workforce. Such structural barriers create challenges at all levels of the workforce development ladder, from recruitment to education, promotion, and retention of HIV providers including researchers, community health workers, and other health care providers.

Together with the development of a diverse health workforce, research that effectively reduces and eliminates health disparities in HIV will require the participation of all sectors of the community. Inclusion of all sectors is fundamental to better understand current needs and develop effective actions to mitigate existing gaps in HIV research and service delivery.

A multipronged approach will be necessary to achieve the interrelated goals of a more diverse and appropriately trained research and health workforce and improved community engagement. Successful approaches should address both individual factors and social factors and involve funding agencies, academic institutions, professional societies, and peer collaboration.

Strategies

3.5.1 Promote the expansion of existing programs and initiatives designed to increase the numbers of non-White research and health professionals.

3.5.2 Increase support for the implementation of mentoring programs for individuals from diverse cultural backgrounds to expand the pool of HIV research and health professionals.

3.5.3 Encourage the implementation of effective recruitment of community partners through community-based participatory research and social networking approaches.

Objective 3.6: Advance HIV-related communications to achieve improved messaging and uptake, as well as address misinformation and health care mistrust

Accurate and accessible health communication is essential to ending the HIV epidemic. Communication science provides the tools and strategies for developing communications tailored to the needs of people with HIV and experiencing risk for HIV. Effective HIV communication science involves best practice principles applied to communicator choice and the design, content, tone, and timing of messages. Communications must be responsive to life contexts, community circumstances and feedback, and changes over time.

The U.S. Surgeon General's "Advisory on Building a Healthy Information Environment" states that the nation has the power to build a healthier information reality.[141] Such an environment improves health by enabling informed decision-making and bolsters trust. Dissemination of accurate and accessible health information has been pivotal in the success of HIV prevention and treatment strategies. HIV health communication plays a significant role in decreasing transmission, increasing treatment, and reducing stigma.

Health communication science is a key to understanding and addressing inaccurate health information, whether unintentional misinformation or deliberate and strategic disinformation. Increased investment in new communication implementation research will improve HIV-related health communication strategies and decrease vulnerability to misinformation and disinformation. Addressing communication challenges requires a sustained whole-of-government approach and engagement with multi-sector partnerships and communities.

Strategies

3.6.1 Develop and test strategies to promote accurate creation, dissemination, and uptake of information and to counter associated misinformation and disinformation.

3.6.2 Increase diversity and cultural competence in health communication research, training, and policy.

3.6.3 Expand community engagement in health communication initiatives and research.

3.6.4 Include critical analysis and health communication skills in HIV programs to provide participants with the tools to seek and identify accurate health information and to advocate for themselves and their communities.

3.6.5 Expand effective communication strategies between providers and consumers to build trust, optimize collaborative decision-making, and promote success of evidence-based prevention and treatment strategies.

INDICATORS OF PROGRESS

Working together to pursue these objectives, the nation can achieve the following targets by 2025:

Indicator 7 Decrease stigma among people with diagnosed HIV by 50% from a 2018 baseline median score of 31.2 on a 10-item questionnaire.

Indicator 8 Reduce homelessness among people with diagnosed HIV by 50% from a 2017 baseline of 9.1%.

Indicator 9 Increase the median percentage of secondary schools that implement at least 4 out of 7 LGBTQ-supportive policies and practices to 65% from a 2018 baseline of 59.8%

In addition to these indicators, the Strategy identifies a disparities indicator to measure progress toward reducing significant HIV-related disparities. Core indicator 6 on viral suppression serves as this disparities indicator and is stratified by each of the priority populations identified in the Strategy:

Indicator 6a Increase viral suppression among MSM diagnosed with HIV to 95% from a 2017 baseline of 66.1%.

Indicator 6b Increase viral suppression among Black MSM diagnosed with HIV to 95% from a 2017 baseline of 58.4%.

Indicator 6c Increase viral suppression among Latino MSM diagnosed with HIV to 95% from a 2017 baseline of 64.9%.

Indicator 6d Increase viral suppression among American Indian/Alaska Native MSM diagnosed with HIV to 95% from a 2017 baseline of 67.3%.

Indicator 6e Increase viral suppression among Black women diagnosed with HIV to 95% from a 2017 baseline of 59.3%.

Indicator 6f Increase viral suppression among transgender women in HIV medical care to 95% from a 2017 baseline of 80.5%.

Indicator 6g Increase viral suppression among people who inject drugs diagnosed with HIV to 95% from a 2017 baseline of 54.9%.

Indicator 6h Increase viral suppression among youth aged 13–24 diagnosed with HIV to 95% from a 2017 baseline of 57.1%.

GOAL 4: ACHIEVE INTEGRATED, COORDINATED EFFORTS THAT ADDRESS THE HIV EPIDEMIC AMONG ALL PARTNERS AND INTERESTED PARTIES

THE OPPORTUNITY

Since the NHAS was first published in 2010, it has inspired all sectors of society—including government agencies, nongovernmental organizations, and the private sector—to better coordinate the nation's response to the HIV epidemic. This iteration of the Strategy continues to recognize the importance of more integrated, coordinated efforts.

Even greater coordination is possible and essential to ending the HIV epidemic in America. Opportunities include partnerships to meet unmet needs, maximize reach, share best practices to overcoming common challenges, leverage available data, use new and evolving technologies, and promote efficiency and sustainability. Greater integration of services is crucial to meeting the nation's HIV testing, prevention, care, treatment, and supportive service needs, especially for people living in under-resourced areas and/or who are not effectively reached and engaged by existing programs and services.

It is also essential to address the syndemic of HIV, STIs, viral hepatitis, and alcohol and substance use and mental health disorders. Collaborative efforts cannot be a one-way street, only benefiting the goals of HIV programs; rather, they should address how HIV programs can facilitate the attainment of other programs' goals that contribute to the overall health and well-being of the populations served.

Activities that exemplify improved integration and coordination of efforts include the following:

- **CDC and HRSA's joint guidance to health departments and planning groups about single, multi-year Integrated HIV Prevention and Care Plans.** In June 2021, CDC and HRSA issued Integrated Plan Guidance for CY 2022-2026, which intends to accelerate progress toward meeting national goals while allowing each jurisdiction to design an HIV services delivery system that reflects local vision, values, and needs. This guidance built on the first such guidance issued in 2015;[142] reduced duplicative planning and reporting for grantees; streamlined the work of health department staff and HIV planning groups; and promoted improved collaboration and coordination in the use of data to inform HIV prevention and care program planning, resource allocation, evaluation, and continuous quality improvement.
- **Integration of CDC funding for health department HIV surveillance and prevention.** In 2018, CDC renewed and strengthened its flagship funding program to support HIV surveillance and prevention efforts led by state, territorial, and local health departments with 5-year funding awards that integrated HIV surveillance and prevention programs for the first time. Integration helps health departments plan and execute more efficient, coordinated, and data-driven prevention efforts.
- **Pilot programs that have demonstrated the effectiveness of collaborative data-to-care (D2C) approaches.** Using HIV surveillance and other data to improve continuity of HIV care, these CDC-supported pilot programs integrated data from public health and health care delivery to identify people with an HIV diagnosis who were not engaged in medical care and facilitated linkage to care. The pilots demonstrated effectiveness in achieving their goal of increasing the number of people with HIV who are reengaged in care and virally suppressed.[143]
- **Integration of data across programs to improve design and delivery of services.** HRSA and the Department of Housing and Urban Development collaborated to better coordinate HIV care and housing services for people with HIV through data integration and to ultimately improve health outcomes along the HIV care continuum.[144]

- **HRSA, NIH, and CDC Implementation Science Workgroup.** In 2018 the HRSA HIV/AIDS Bureau began a close collaboration with the CDC Division of HIV/AIDS Prevention and the National Institutes of Health's National Institute of Mental Health to create a platform for dialogue across federal agencies working to apply implementation science in HIV, establishing the Federal Implementation Science Workgroup. The resulting funding opportunity announcements seek to strengthen research/service delivery collaborations between NIH investigators and implementers such as sites funded by CDC, HRSA, the Indian Health Service (IHS), the Substance Abuse and Mental Health Services Administration (SAMHSA), and other providers of HIV prevention and care services. Applicants develop creative, locally defined, and culturally sensitive concepts that align with the EHE jurisdictional plans.[145]
- **A growing awareness of the need to better integrate services for populations vulnerable to multiple health concerns.** For example, a 2019 National Academies of Sciences, Engineering, and Medicine workshop highlighted the importance of addressing infectious diseases as part of an improved, comprehensive opioid response and noted that separately administered substance use disorder treatment and infectious disease services often inhibit comprehensive care.[146] In addition, in 2020 SAMHSA published Prevention and Treatment of HIV Among People Living with Substance Use and/or Mental Disorders, a guide that addresses the co-occurrence of HIV and mental illness and/or substance use disorders and reviews effective programs and practices to prevent HIV and, for people with HIV, to increase linkage and retention in care in order to improve health outcomes.
- **Use of new HIV surveillance techniques.** CDC has supported several jurisdictions to detect possible HIV infection clusters more quickly and then coordinate swift responses across programs to deliver needed prevention and treatment services to people who need them. As work continues to expand the ability to identify and quickly respond to new HIV infections, health departments and communities must work together to collectively address the consent, privacy, and data use concerns.
- **Provisions in the 21st Century Cures Act on the interoperability of health information.** These provisions, including those related to social determinants of health, put the patient at the center of care and promote secure health information exchange to enable improved coordination, targeting of resources, and research that can support achieving the Strategy's goals. In March 2020, the Office of the National Coordinator for Health IT (ONC) issued a final rule to implement key interoperability provisions of the 21st Century Cures Act, including promoting patient access to their electronic health information, supporting provider needs, advancing innovation, and addressing industry-wide information blocking practices.[147]

GOAL 4: ACHIEVE INTEGRATED, COORDINATED EFFORTS THAT ADDRESS THE HIV EPIDEMIC AMONG ALL PARTNERS AND INTERESTED PARTIES

Objectives

4.1 Integrate programs to address the syndemic of HIV, STIs, viral hepatitis, and substance use and mental health disorders in the context of social and structural/institutional factors including stigma, discrimination, and violence

4.2 Increase coordination among and sharing of best practices from HIV programs across all levels of government (federal, state, tribal, local, and territorial) and with public and private health care payers, faith-based and community-based organizations, the private sector, academic partners, and the community

4.3 Enhance the quality, accessibility, sharing, and uses of data, including HIV prevention and care continua data and social determinants of health data

4.4 Foster private-public-community partnerships to identify and scale up best practices and accelerate HIV advances

4.5 Improve mechanisms to measure, monitor, evaluate, and use the information to report progress and course correct as needed in order to achieve the Strategy's goals

- **Partnerships with Medicaid programs.** Through these partnerships, several state HIV programs have been able to implement performance measures that reward providers who have increased the numbers of patients who have achieved and maintained viral suppression.
- **Enhanced efforts to integrate services and disciplines in health care delivery.** In recent years, greater emphasis has been placed on integrating behavioral health (mental health and substance use disorder) services and primary care and vice versa. Expanding availability of medications for treatment for substance use disorders in primary care settings is one example. Similarly, to serve the growing population of people with HIV over age 50, more clinics are adopting a geriatric multidisciplinary approach to health care, addressing the domains of medical problems, cognitive and functional abilities, psychiatric disorders, and social circumstances.[148]
- **Updating the United States Core Data for Interoperability (USCDI) as a Foundation for Interoperability.** In July 2021, ONC released version 2 of the USCDI. The update expands the standardized set of health data classes and elements for nationwide, interoperable health information exchange. The new data elements support efforts to advance health equity by addressing sexual orientation, gender identity, and social determinants of health.[149]

THE CHALLENGES

The following challenges hinder efforts to achieve more integrated and coordinated efforts that address the HIV epidemic among all partners and interested parties:

- Rising rates of substance use have resulted in concurrent infectious diseases epidemics.
- Coordination at the federal, state, and local levels has not expanded to include other necessary government, community-based, and civic partners.
- Data sharing and integration is not timely across programs.
- Local HIV plans are not adequately supported.
- The COVID-19 pandemic continues to divert resources.
- Legislation, budget allocations, and payment systems are not aligned with models of integrated care.

SUMMARY OF OBJECTIVES

The following objectives are critical to achieving integrated, coordinated efforts that address the HIV epidemic among all partners and interested parties:

4.1 Integrate programs to address the syndemic of HIV, STIs, viral hepatitis, and substance use and mental health disorders in the context of social and structural/institutional factors including stigma, discrimination, and violence.

4.2 Increase coordination among and sharing of best practices from HIV programs across all levels of government (federal, state, tribal, local, and territorial) and with public and private health care payers, faith-based and community-based organizations, the private sector, academic partners, and the community.

4.3 Enhance the quality, accessibility, sharing, and use of data, including HIV prevention and care continuum data and social determinants of health data.

4.4 Foster private-public-community partnerships to identify and scale up best practices and accelerate HIV advances.

4.5 Improve mechanisms to measure, monitor, evaluate, and use the information to report progress and course correct as needed in order to achieve the Strategy's goals.

OBJECTIVES AND STRATEGIES

Objective 4.1 Integrate programs to address the syndemic of HIV, STIs, viral hepatitis, and substance use and mental health disorders in the context of social and structural/institutional factors including stigma, discrimination, and violence

The syndemic of HIV, STIs, viral hepatitis, substance use and mental health disorders in the United States highlights overlapping risk factors as well as associations with social determinants of health such as poverty, lack of health insurance, housing instability, and other related inequities. An effective response to the syndemic requires integration of programs to enable increased flexibility in utilization of allocated resources; better coordinated policy and program planning, development, and delivery; and rapid adjustment to new data or scientific advances. For such integration to occur, major shifts in policy, systems, and societal norms and attitudes must occur, and the willingness to explore new and nontraditional approaches and strategies must increase.

A National Academies report recommends that the syndemic be addressed via integrated medical services in place of often siloed services.[146] Opportunities are missed every day to test people for multiple infections and to scale up HIV services in settings where people who experience risk receive other services. For example, in 2019 among health care settings and non-health-care settings, only 34% of CDC-funded HIV tests had at least one STI or hepatitis C test conducted concurrently.[150] These missed opportunities translate directly into lost time and resources and may result in harm to people who remain undiagnosed, untreated, and at risk of severe outcomes or of transmitting the infection to others. A reciprocal, integrated approach in responses to infectious diseases, the opioid crisis, and substance use and mental health disorders that puts patients first through a status-neutral and no-wrong-door approach will maximize their ability to access services that meet their health needs. In addition, creating a system that focuses on a whole-health approach and one that considers a myriad of needs can lead to enhanced life experiences for people living with HIV. For example, HIV testing programs can identify opportunities to screen for other STIs, viral hepatitis, substance use, and intimate partner violence. Similarly, STI, substance use disorder treatment, and viral hepatitis programs can integrate HIV testing and linkage to relevant HIV prevention or care services, as appropriate.

Strategies

4.1.1 Integrate HIV awareness and services into outreach and services for issues that intersect with HIV such as intimate partner violence, homelessness or housing instability, STIs, viral hepatitis, and substance use and mental health disorders.

4.1.2 Implement a no-wrong-door approach to screening and linkage to services for HIV, STIs, viral hepatitis, and substance use and mental health disorders across programs.

4.1.3 Identify and address funding, policy, data, workforce capacity, and programmatic barriers to effectively address the syndemic.

4.1.4 Coordinate and align strategic planning efforts on HIV, STIs, viral hepatitis, substance use disorders, and mental health care across national, state, tribal, territorial, and local partners.

4.1.5 Enhance the ability of the HIV workforce to provide naloxone and educate people on the existence of fentanyl in the drug supply to prevent overdose and deaths and facilitate linkage to substance use disorder treatment and harm reduction programs.

Objective 4.2 Increase coordination among and sharing of best practices from HIV programs across all levels of government (federal, state, tribal, local, and territorial) and with public and private health care payers, faith-based and community-based organizations, the private sector, academic partners, and the community

Ending the HIV epidemic requires a whole-of-society approach. Increasing coordination across all sectors of society enables better delivery of services and resources to people with or who experience risk for HIV. Likewise, establishing trusted partnerships enables coalitions to develop, implement, and regularly evaluate and update policies and programs that address the social, economic, and political environments that shape and constrain individual, community, and societal outcomes.

Increased coordination at the federal level includes expanding the partners engaged in the nation's HIV response. This effort includes leveraging existing programs whose primary purpose may not be HIV services, but that could provide supportive services such as employment training or nutrition assistance to people with or who experience risk for HIV. Such coordination helps to ensure that resources are allocated according to current burden of disease and that the most effective prevention and care strategies are tailored to local community needs to achieve maximal results.

Better coordination involves fostering strong linkages among community-based organizations, health departments, other public programs and services, education agencies, pharmacies, health care providers and systems, and community leaders. Collaboration with community partners is particularly important to developing locally relevant plans for providing testing, prevention, care, treatment, and supportive services, including those that engage people not yet reached by existing programs and services. Collaboration also involves engaging and building capacity and competencies among partners and communities that are interested in providing HIV services but may not have had the opportunity or resources to do so. Expanded and strengthened partnerships can better equip communities to respond swiftly and effectively to identified outbreaks of HIV, STIs, and/or viral hepatitis. Greater involvement by our nation's technology and other business communities can boost efforts to provide accurate information, reach key populations, and develop innovative tools.

Attention must also be focused on service delivery and payment methods. Fee-for-service and other payment models do not adequately support integrated, comprehensive health care delivery models, such as behavioral health and medical care integration, patient-centered medical homes, services provided by pharmacists in nontraditional roles, integration with support services, oral health care, and care coordination. Grant funding to support pilots or demonstrations of such integrated models is limited and time-bound. Scaling up and sustaining these effective care delivery models require evolutions in public and private payer systems.

Strategies

4.2.1 Focus resources including evidence-based and evidence-informed interventions in the geographic areas and priority populations disproportionately affected by HIV.

4.2.2 Enhance collaboration among local, state, tribal, territorial, national, and federal partners and the community to address policy and structural barriers that contribute to persistent HIV-related disparities and implement policies that foster improved health outcomes.

4.2.3 Coordinate across partners to quickly detect and respond to HIV outbreaks.

4.2.4 Support collaborations between community-based organizations, public health organizations, education agencies and schools, housing providers, and health care delivery systems to provide linkage to and delivery of HIV testing, prevention, care, and treatment services as well as supportive services.

Objective 4.3 Enhance the quality, accessibility, sharing, and uses of data, including HIV prevention and care continua data and social determinants of health data

High-quality data are essential to increasing coordination, integration, and seamless delivery of services that are required to end the HIV epidemic. The appropriate collection and use of data can inform efforts to focus prevention and testing services on populations that need them most, can help ensure that people newly diagnosed with HIV are promptly linked to care, and can facilitate retention in effective HIV care. However, jurisdictions need resources, guidance, and support to strengthen HIV surveillance systems and activities, in accordance with applicable law, to obtain the data needed to improve our response to the HIV epidemic, including viral load reporting and disparities data to ensure that populations or communities are not being left behind.

Appropriate use of secure electronic health information exchange can help to engage and retain or reengage people in care and to facilitate transitions across care and community settings. Further, sharing of treatment and outcome data can drive the science needed to develop new and better treatments, approaches to retention in care, and prevention interventions. Better use of data on social determinants of health can optimize prevention and testing efforts for groups experiencing greater risk of acquiring HIV, engage and retain people with HIV in care, support adherence to treatment, and inform ongoing research efforts to develop better treatment and prevention. Use of modeling and other analytical approaches may yield novel insights and inform planning.

Strategies

4.3.1 Promote the collection, electronic sharing, and use of HIV risk, prevention, and care and treatment data using interoperable data standards, including data from electronic health records, in accordance with applicable law.

4.3.2 Use interoperable health information technology, including application programming interfaces (APIs), clinical decision support tools, electronic health records and health IT products certified by the Office of the National Coordinator's Health IT Certification Program, and health information exchange networks to improve HIV prevention efforts and care outcomes.

4.3.3 Encourage and support patient access to and use of their individual health information, including use of their patient-generated health information and use of consumer health technologies in a secure and privacy-supportive manner.

Objective 4.4 Foster private-public-community partnerships to identify and scale up best practices and accelerate HIV advances

Effective private-public-community partnerships are necessary to enhance responses to critical implementation challenges. Partnerships should ensure local relevance and emphasize the leadership role of community members, academic investigators, public health departments and other collaborators through intentional involvement in all stages of research, from conceptualization of the research question to dissemination of results.

There is growing interest in developing closer partnerships among the private sector to increase the appropriate application of evidence in policy and practice. Private-sector resources and approaches that integrate multidisciplinary HIV prevention and treatment service delivery in different settings can reach communities in ways that government cannot. Emphasis on cross-disciplinary collaboration and input by allied health and community service providers as partners with the private sector in HIV research, prevention, and care will optimize program acceptability, uptake, and rollout; improve outcomes; and maximize the impact of translation of research results.

The response to the HIV epidemic has generated significant scientific advances and best practices. Implementation science provides a framework to identify factors that facilitate application of relevant and effective public health interventions and services. Community-centric implementation research is one important approach to rapidly and effectively translate new discoveries into practice at the local level, with fidelity. Effective partnerships can achieve an impact at the population level, to efficiently disseminate evidence-based interventions at scale through culturally appropriate public health initiatives and clinical practice (see Box 9).

There is a need to develop more opportunities and mechanisms for timely information sharing and peer technical assistance to support replication of best practices and use of lessons learned to address common barriers within and across jurisdictions. Activities supporting replication and scale-up of proven interventions should address infrastructure needs and include intentional sustainability planning to ensure continuity of care and services across all participating service settings.

Strategies

4.4.1 Adopt approaches that incentivize the scale up of effective interventions among academic centers, health departments, community-based organizations, allied health professionals, people with HIV and their advocates, the private sector, and other partners.

4.4.2 Expand opportunities and mechanisms for information sharing and peer technical assistance within and across jurisdictions to move effective interventions into practice more swiftly.

4.4.3 Develop and optimize collaborative multi-agency and multi-sectoral approaches and strategies to address emergent and evolving challenges facing people of all ages living with HIV.

BOX 9

LEVERAGING TECHNOLOGY INNOVATIONS TO IMPROVE HIV PREVENTION AND TREATMENT

Technological innovations have rapidly altered many aspects of life in the past decade. Many Americans have transformed their digital toolbox to include systems such as Zoom or FaceTime, email, and other applications to stay informed on their health and connected to health care systems. These innovations prove the potential to leverage technology in the HIV response.

Telehealth has proven to be a reliable resource for reaching populations experiencing risk or who are living with HIV and can address many of the factors identified as barriers to retention in HIV care. Telehealth can also broaden access to pre-exposure prophylaxis (PrEP), HIV care and treatment, and mental health and substance use treatment in rural areas, which often face workforce shortages and transportation challenges.[151] Refining and sustaining telehealth services that were implemented in response to the COVID-19 pandemic will allow organizations to use these technological advances to improve the HIV response.

Expanded use of the internet and social media can help people involved in HIV prevention and treatment use mobile devices, websites, and applications as hubs for HIV information and collaboration to ensure that scientifically and medically accurate information is prioritized, and misinformation is combated. At the same time, these websites and applications can also make accessing information on HIV prevention, testing, and treatment more accessible and discrete. Wearable technology such as smartwatches can use health applications to provide real-time insights on an individual's health status and empower people to personalize and monitor their own health data. Electronic health records strengthen the HIV care continuum by providing accurate and timely information. Electronic health records can also use clinical decision support tools to help improve screening by identifying patients for whom an HIV test or PrEP might be recommended or facilitating reengagement in HIV care for those who may have left but present for other health care services elsewhere. Further advancements in the use of technology to improve HIV care could also be used to streamline patient pathways including enhanced remote patient monitoring techniques and other engagement opportunities made available through emerging fields such as digital therapeutics and at-home testing. Policymakers, clinicians, and private-sector partners must collaborate to uncover solutions and further innovation to leverage technology in the HIV response and improve patient engagement.

Objective 4.5 Improve mechanisms to measure, monitor, evaluate, and use the information to report progress and course correct as needed in order to achieve the Strategy's goals

There is a continued need to streamline and harmonize data reporting to reduce reporting burden and produce more regular, timely, and useful data. Support is also needed to adopt new analytic methods and approaches to increase the timeliness of data, enhance the ability to characterize the burden of HIV across the nation, and use that information to allocate resources to achieve the greatest impact. In addition, complementary data sources such as health care payer databases, surveys, and linkages to electronic health records are necessary to ensure that robust information that can guide decision-making.

Timely data will improve accountability among federally funded organizations as they set and make progress toward measurable goals and targets aligned with this Strategy. Data for the indicators at the local, state, and national levels should be regularly and publicly reported and reviewed to identify successful efforts, indicate challenges, and facilitate ongoing dialogue about ways to continue moving forward. Such reporting and review require a monitoring plan that evaluates the implementation of the Strategy. A system of regular public reporting will help to sustain public attention and support at the national level. Organizations that struggle to engage new parties and organizations or fall short of expected outcomes should receive intensive capacity-building assistance and other supportive measures as a condition of continued funding. The nation can thus direct its funds to entities and initiatives that demonstrate the highest level of performance and accountability for high-impact HIV prevention.

Strategies

4.5.1 Streamline and harmonize reporting and data systems to reduce burden and improve the timeliness, availability, and usefulness of data.

4.5.2 Monitor, review, evaluate, and regularly communicate progress on the National HIV/AIDS Strategy.

4.5.3 Ensure that the National HIV/AIDS Strategy's goals and priorities are included in cross-sector federal funding requirements.

4.5.4 Strengthen monitoring and accountability for adherence to requirements, targets, and goals by funded partners.

4.5.5 Identify and address barriers and challenges that hinder achievement of goals by funded partners and other interested parties.

IMPLEMENTATION AND ACCOUNTABILITY

FEDERAL PARTNERS

The Strategy provides a framework for ending the HIV epidemic in the United States. Development of the Strategy was a collaborative process led by the White House that engaged federal partners across multiple departments and agencies with input from a diverse range of interested parties and organizations from across the nation.

Federal partners will collaborate to develop an implementation plan to pursue the Strategy goals, objectives, and strategies. The NHAS Federal Implementation Plan will set forth federal partners' commitments to policies, initiatives, and activities to meet the goals of the Strategy and will be published for transparency and accountability.

As part of their ongoing commitment to reduce HIV in this nation, federal partners have committed to serve on a Strategy implementation working group. This working group will collaborate to address HIV in an integrated fashion by including other infectious diseases as components of the syndemic. The working group will meet regularly to coordinate activities across agencies and departments, apply lessons learned from epidemiological data and research findings, monitor progress toward the indicator targets, course correct as needed, and report on national progress. As scientific, medical, and public health advances and challenges emerge, new and innovative policies will be developed to complement the existing Strategy.

NONFEDERAL PARTNERS

Addressing HIV is not solely a federal activity. Success depends on coordinated action by state, tribal, territorial, and local governments; community-based organizations and faith-based organizations; health plans and payers, health care providers, and other health-related organizations; private-sector partners; the criminal justice system; universities, schools, education agencies, and other venues for educational activities; researchers; families; and patients and their partners. Its success also depends on a holistic approach to the various parts of the syndemic, including STIs, viral hepatitis, substance use and mental health disorders, stigma and discrimination, and social and structural determinants of health.

Each community and stakeholder brings a unique perspective and plays a critical role in preventing and responding to HIV. Over the past several years many states and localities have engaged in community-wide efforts to develop their own plans to end the HIV epidemic. Interested parties and organizations are encouraged to use this Strategy to engage with others and build or update their own roadmap to reduce HIV and end the HIV epidemic among the populations and communities they serve. Interested parties and organizations should consider adopting the vision and goals of this Strategy; pursuing the objectives and implementing the strategies relevant to their role(s), populations served, and community circumstances; and identifying opportunities to adopt and use the Strategy's indicators and targets to measure their own progress. In doing so, communities and interested parties and organizations can also apply other evidence-based strategies that are appropriate for responding to HIV in their area and use all available data to identify where their resources and effort will have the most impact. A data-driven strategy will help interested parties and organizations focus efforts and efficiently and effectively use available resources. Integrating HIV testing, prevention, care, and treatment efforts with other components of the syndemic is also strongly encouraged.

APPENDIX A: PROCESS FOR DEVELOPING THE STRATEGY

On June 5, 2021, the Biden-Harris administration re-established the Office of National AIDS Policy (ONAP) within the White House. After discussions with staff of the White House Domestic Policy Council, it was agreed that the HIV National Strategic Plan (HIV Plan) released in January 2021 provided a strong foundation for ending the HIV epidemic but required updates to reflect Administration priorities, the latest data and research, and community feedback specific to the HIV Plan.

ONAP consulted with the federal department and agency representatives who served on the interagency Steering Committee that developed the HIV Plan (see Table A.1) to obtain recommendations to fulfill this mandate. In addition, ONAP received feedback from a variety of parties from the HIV community that could strengthen the Strategy to end the HIV epidemic by 2030. ONAP reviewed, considered, and integrated much from these various inputs into this Strategy, with support from the White House Office of National Drug Control Policy and the Office of Infectious Disease and HIV/AIDS Policy (OIDP), within the Office of the Assistant Secretary for Health at the Department of Health and Human Services (HHS). Drafts were refined through successive rounds of review by the Steering Committee, Domestic Policy Council, inter-departmental clearance, and the White House.

Table A.1. Composition of NHAS Federal Steering Committee

Federal Departments and Agencies	HHS Agencies/Offices	
• Department of Agriculture • Department of Defense • Department of Education • Department of Justice • Equal Employment Opportunity Commission • Department of Health and Human Services • Department of Housing and Urban Development • Department of Labor • Department of Veterans Affairs	• Administration for Community Living • Agency for Healthcare Research and Quality • Centers for Disease Control and Prevention • Centers for Medicare & Medicaid Services • Food and Drug Administration • Health Resources and Services Administration • Indian Health Service	• National Institutes of Health • Office for Civil Rights • Office of the Assistant Secretary for Health • Office of the National Coordinator for Health Information Technology • Substance Abuse and Mental Health Services Administration

IDENTIFICATION OF PRIORITY POPULATIONS BASED ON NATIONAL-LEVEL DATA

ONAP maintained in this Strategy the priority populations designated in the HIV National Strategic Plan. Priority populations are disproportionately affected populations, which are defined as groups of people with a higher burden of disease than others. HIV testing, prevention, care, and treatment interventions and resources can be delivered to priority populations for the greatest impact. An Indicators Subcommittee of the Steering Committee that developed the HIV National Strategic Plan reviewed national HIV surveillance data available in 2020 to identify priority populations. In developing this Strategy, ONAP reviewed the most recent data and determined that it continued to support the designation of the identified priority populations.

Table A.2. Priority Populations and Summary National-Level Data, Calendar Year 2019 (unless otherwise indicated)

Gay, Bisexual, and Other Men Who Have Sex with Men (MSM)

- Gay, bisexual, and other men who have sex with men are the population most affected by HIV in the United States. At the end of 2019, an estimated 1,189,700 people had HIV in the United States. Of those, 692,900 (58%) were gay and bisexual men.[11]
- In 2019, adult and adolescent gay and bisexual men represented 66% (23,100) of the 34,800 new HIV infections in the United States.[11]
- The incidence of many STIs in gay, bisexual, and other men who have sex with men—including primary and secondary syphilis and antimicrobial-resistant gonorrhea—is greater than that reported in women and men who have sex with women only.[152] Having another STI can greatly increase the chance of getting or transmitting HIV. Of new HIV infections among men who have sex with men, 10% are estimated to be attributable to gonorrhea and chlamydia, equating to 2,600 HIV infections each year.[51]

Black MSM

- Black gay, bisexual, and other men who have sex with men are more affected by HIV than any other group in the United States.
- In 2019, Black gay and bisexual men accounted for 26% (8,900) of the 34,800 new HIV infections and 39% of the 23,100 new infections among all gay and bisexual men in the United States.[11]
- Of the 36,337 new HIV diagnoses among adolescents and adults ≥13 years in the United States and dependent areas in 2019, 25% were among Black gay and bisexual men.[3]
- From 2015 to 2019, HIV infections remained stable among Black gay and bisexual men overall. By age group, the annual number of new HIV infections declined in Black gay and bisexual men aged 13–24, while the number of new infections remained stable among all other age groups of Black gay and bisexual men.[11] In 2019 the largest percentage of new HIV infections among Black/African American gay and bisexual men was among those aged 25–34 years (46%), followed by those aged 13–24 years (33%).[11]
- Along the HIV care continuum, compared to all people with diagnosed HIV in 41 states and the District of Columbia, Black gay and bisexual men have lower viral suppression rates.[7] (See Figure A.1.)

Latino MSM

- Latino gay, bisexual, and other men who have sex with men are heavily affected by HIV. In 2019, adult and adolescent Latino gay and bisexual men comprised 23% (7,900) of the 34,800 new HIV infections in the United States and 34% of 23,100 new HIV infections among all gay and bisexual men in the United States.[11]
- Of the 36,337 new HIV diagnoses among adolescents and adults ≥13 years in the United States and dependent areas in 2019, 22% were among Latino gay and bisexual men.[3]
- From 2015 to 2019, the annual number of new HIV infections declined in Hispanic/Latino gay and bisexual men aged 13-24, while the number of new infections remained stable among all other age groups of Hispanic/Latino gay and bisexual men.[11] In 2019 the largest percentage of HIV infections among Hispanic/Latino gay and bisexual men was among those aged 25-34 years (44%), followed by those aged 13–24 years (23%).[11]

American Indian/Alaska Native MSM

- American Indian/Alaska Native men who have sex with men are disproportionately affected by HIV. In 2019, 62% (126/209) of diagnoses among adolescents and adults ≥13 years occurring among American Indian/Alaska Native people were among men who have sex with men.[3]
- HIV diagnoses among American Indian/Alaska Native gay and bisexual men increased 15% between 2015–2019, while diagnoses among gay and bisexual men of other races/ethnicities were either stable or declined.[125]

Black Women

- Although data show a 22% decrease in new HIV infections among Black women between 2010 and 2019, among all women in the United States, Black women account for the largest share of 6,400 new HIV infections (3,400 or 53%) in 2019.[4, 11]
- The rate of new HIV infections among Black women (18.9 per 100,000) is nearly 11 times as high as the rate among White women (1.8 per 100,000) and nearly 4 times as high as the rate among Latinas (4.9 per 100,000).[11]

Transgender Women

- A 2019 systematic review and meta-analysis found that an estimated 14% of transgender women have HIV.[14]
- By race/ethnicity, an estimated 44% of Black transgender women, 26% of Latina transgender women, and 7% of White transgender women have HIV.[2, 3, 153]
- Among the 3 million HIV testing events reported to CDC in 2017, the percentage of transgender people who received a new HIV diagnosis was three times the national average.[154]

Youth Aged 13–24 Years

- In 2019, youth aged 13–24 years accounted for 21% (7,200) of the 34,800 new HIV infections in the United States and dependent areas. Most new HIV diagnoses among youth were among young gay and bisexual men.
- Only 9% of high school students have been tested for HIV and therefore do not know their HIV status. Among male students who had sexual contact with other males, only 15% have ever been tested for HIV.[155]
- In 2019, youth with diagnosed HIV were also the least likely of any age group to be linked to care within 1 month of diagnosis (79%).[2] Further, compared to all people with HIV, youth have the lowest rates of viral suppression. For every 100 youth with HIV, 45 received some HIV care, 33 were retained in care, and 35 were virally suppressed.[2]
- People aged 15–24 years account for approximately 50% of the 20 million new STIs in the United States each year, yet approximately 25% of the sexually active population.[152] Having another STI can greatly increase the chance of getting or transmitting HIV.

People Who Inject Drugs (PWID)

- People who inject drugs are at high risk for getting HIV and/or HCV if they use and share needles, syringes, or other drug injection equipment that someone with HIV has used.
- New HIV infections among people who inject drugs have increased 8.7% in recent years (from 2,300 infections in 2015 to 2,500 infections in 2019) in the United States and dependent areas.[11]
- Although HIV incidence among people who inject drugs has declined substantially over many years, the ongoing use of opioids and other frequently injected substances including cocaine and methamphetamine are threatening this HIV prevention success. HIV diagnoses among people who inject drugs increased by 11% nationally from 2016 to 2018, with more pronounced increases among adults younger than age 40 and non-Hispanic White adults.[125] Injection drug use has contributed to multiple recent clusters and outbreaks of new HIV infections among people who inject drugs.[156]
- Among people with HIV who inject drugs, 62–81% were also living with hepatitis C.[157] People with HIV also living with hepatitis B or hepatitis C have higher liver-related morbidity and mortality, and higher overall mortality than patients only living with hepatitis B or hepatitis C.[158-160]

Figure A.1 depicts the subpopulations (defined by race, ethnicity, and gender) with the most new HIV diagnoses in 2019.

* * *

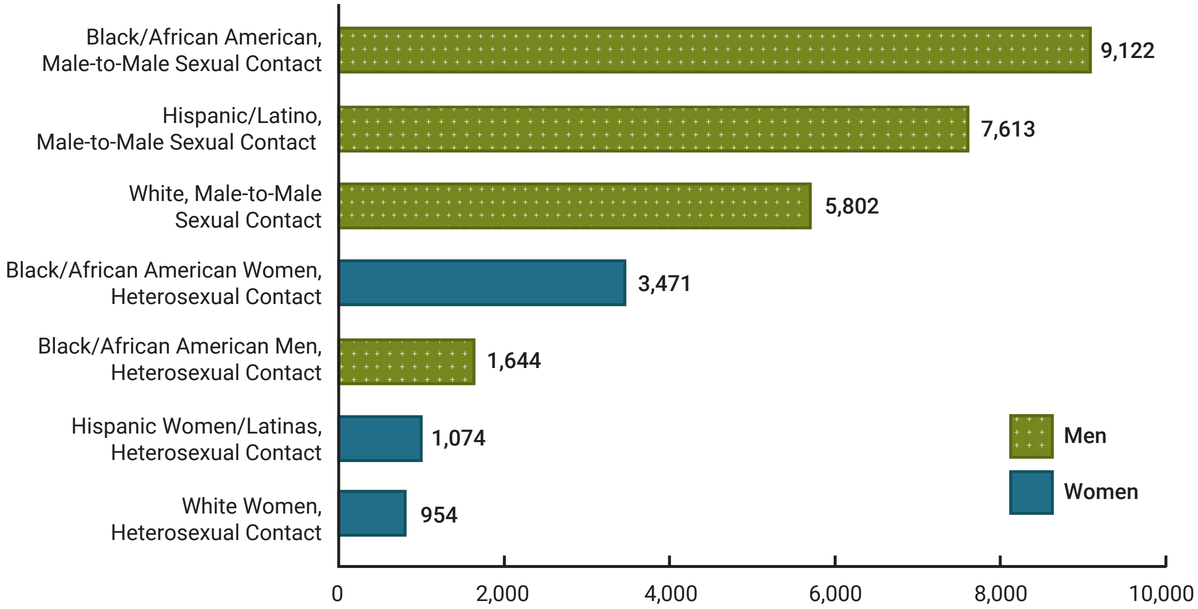


Figure A.1. New HIV diagnoses in the United States and dependent areas for the most-affected subpopulations, 2019

Notes: Black refers to people having origins in any of the Black racial groups of Africa. African American is a term often used for Americans of African descent with ancestry in North America. Hispanics/Latinos can be of any race. Subpopulations representing 2.0% or less of all people who received an HIV diagnosis in 2018 are not represented in this chart. Source: Centers for Disease Control and Prevention.[161]

The Strategy recognizes the importance of providing HIV services to all populations with or who experience risk for HIV. Therefore, even though they were not designated as priority populations, the Strategy discusses the importance of addressing the unique needs of other groups, such as long-term survivors and older people with HIV or people experiencing unstable housing or homelessness.

INDICATORS TO MEASURE PROGRESS FOR THE NATIONAL HIV/AIDS STRATEGY

The Strategy includes 9 core indicators to monitor annual progress toward achieving Goals 1, 2, and 3. In addition, one of the core indicators is stratified by each of the priority populations to measure progress toward reducing disparities.

For each indicator, baseline measurements (2017) and targets for 2025 are provided. Indicators 1–6 are aligned with the EHE initiative and *Healthy People 2030* objectives. Alignment of the indicators between the HIV Plan and EHE allows for consistency and reduced burden on local and state health departments that report data as well as on federal partners who monitor and report on progress in measuring and reporting results across the indicators.

The methods for measuring progress and specifications for each of the indicators is detailed below.

METHODS

CDC's National Center for Health Statistics describes the "percent of targeted change achieved," which quantifies progress for *Healthy People 2020* indicators that are moving toward their targets. The methods are described in full by Talih and Huang[162] and may be used for measuring progress in *Healthy People 2030*. To align methods for measuring progress across HHS, the percentage of targeted change achieved method is adapted for use to measure national progress annually for the National HIV/AIDS Strategy.

METHODS

The "percent of targeted change achieved" used in *Healthy People 2020* is the difference between the baseline and the midcourse value as a percent of the targeted change between the baseline value and the *Healthy People 2020* target. To adapt for use in the National HIV/AIDS Strategy, annual results and National HIV/AIDS Strategy targets are used. This method also provides a way to compare percent of targeted change achieved by National HIV/AIDS Strategy indicator and highlights areas on which to focus. The formula is as follows:

$$\text{Percent of targeted change achieved} = \frac{\text{Annual result - Baseline result x 100}}{\text{2025 target - Baseline result}}$$

The magnitude of change for percent of targeted change achieved may be evaluated using statistical significance testing for indicators that are estimated.

An *example* using hypothetical data is provided below to illustrate the calculations for the percent of targeted change achieved for linkage to care within 1 month and viral suppression.

Table A.3. Hypothetical Data for Linkage to Care and Viral Suppression Calculations

Indicator	2017	2023	2025 Target
Linkage to Care within 1 Month	78.4%	82.3%	95%
Viral Suppression	54.4%	65.5%	95%

Percent of targeted change achieved for *linkage to care within 1 month:*

$$= \frac{82.3\% - 78.4\%}{95\% - 78.4\%} = \frac{3.9}{16.6} = 23.5\%$$

Achieving the 95% target for linkage to care within 1 month is 100% of the targeted change needed by 2025. *Interpretation:* By 2023, almost one-quarter or 23.5% of the targeted change has occurred for linkage to care within 1 month.

Percent of targeted change achieved for *viral suppression:*

$$= \frac{65.5\% - 54.4\%}{95\% - 54.4\%} = \frac{11.1}{40.6} = 27.3\%$$

Achieving the 95% target for viral suppression is 100% of the targeted change needed by 2025. *Interpretation:* By 2023, a little more than one-quarter or 27.3% of the targeted change has occurred for viral suppression.

Indicators that met or exceeded their targets

When the desired direction is increase, an indicator has met or exceeded the target if the annual result is greater than or equal to the 2025 target.

Annual result ≥ 2025 target

When the desired direction is a decrease, an indicator has met or exceeded the target if the annual result is less than or equal to the 2025 target or the 2030 target.

Annual result ≤ 2025 target

Statistical significance is not factored into the determination of the target met or exceeded status.

Indicators moving toward their targets

For indicators that had not already met or exceeded their targets at baseline and are *moving toward* their 2025 targets, the percent of targeted change achieved measures the extent of movement toward the target. The formula is the same as that presented above and is calculated by:

$$\text{Percent of targeted change achieved} = \frac{\text{Annual result - Baseline result x 100}}{\text{2025 target - Baseline result}}$$

When the desired direction is an increase (i.e., increase to 95%), an indicator *is moving toward* its target when the most recent *annual result is higher than the baseline value but less than the 2025 target.*

Baseline result < Annual result < 2025 target

When the desired direction is a decrease (i.e., decrease by 75%), an indicator *is moving toward* its target when the most recent *annual result is less than the baseline value but greater than the 2025 target.*

Baseline result > Annual result > 2025 target

Indicators moving away from their targets

For indicators that had not already met or exceeded their targets at baseline and are moving away from their 2025 targets, the percent of targeted change achieved measures the extent of movement away from the target and is calculated by:

$$\text{Magnitude of percent change from baseline} = \frac{|\text{ Annual result - Baseline result }| \text{ x 100}}{\text{Baseline result}}$$

The absolute value of the percent change from baseline is used to measure movement in this instance. When indicator results are moving away from the 2025 targets, the indicator results will need to make up the deficit from the baseline (i.e., get back to baseline value). Additional work would be needed to see desired targeted change once the baseline value is regained.

INDICATOR SPECIFICATIONS FOR THE NATIONAL HIV/AIDS STRATEGY

Indicator 1: Increase knowledge of status

- Definition:
  - Numerator: Number of persons aged ≥13 years living with diagnosed HIV at end of a measurement year.
  - Denominator: Estimated number of persons aged ≥13 years living with diagnosed or undiagnosed HIV at the end of a measurement year.
- Baseline year: 2017
- Baseline result: 85.8%
- Target: By 2025, increase to 95%.
- Data source: National HIV Surveillance System (NHSS).[11] NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.
- Data availability: Data are published annually.

Indicator 2: Reduce new HIV infections

- Definition: Incidence is the estimated number of new HIV infections among persons aged ≥13 years that occurred in the measurement year and includes diagnosed and undiagnosed infections.
- Baseline year: 2017
- Baseline result: 37,000
- Targets: By 2025, reduce incidence by 75% from baseline. By 2030, reduce incidence by 90% from baseline.
- Data source: National HIV Surveillance System (NHSS).[11] NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.
- Data availability: Data are published annually.

Indicator 3: Reduce new HIV diagnoses

- Definition: Number of persons ≥13 years who have received laboratory or clinical confirmation of HIV in a measurement year.
- Baseline year: 2017
- Baseline result: 38,351
- Targets: By 2025, reduce diagnoses by 75% from baseline. By 2030, reduce diagnoses by 90% from baseline.
- Data source: National HIV Surveillance System (NHSS). NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.[3]
- Data availability: Data are published annually. Preliminary data are also available quarterly.
- Notes: Provisional annual data (annual data with ≥12 months of reporting delay) will be used to measure progress.

Indicator 4: Increase PrEP coverage

- Definition:
  - ◇ Numerator: Number of persons ≥16 years who were classified as having been prescribed PrEP in a measurement year.
  - ◇ Denominator: Estimated number of persons with indications for PrEP in a measurement year.
- Baseline year: 2017
- Baseline result: 13.2%
- Target: By 2025, increase to 50%.
  - ◇ Numerator: IQVIA Real-World Longitudinal Prescriptions database
  - ◇ Denominator: Uses three data sources:
    1. The American Community Survey from U.S. Census is used to estimate the number of men who have sex with men (MSM) in a jurisdiction.[163]
    2. Behavioral data from the National Health and Nutrition Examination Survey (NHANES) are used to estimate the proportion of HIV-negative MSM with indications for PrEP.[164]
    3. The National HIV Surveillance System (NHSS) diagnoses data are used.[2] The number of HIV-negative MSM with indications for PrEP are multiplied by the ratio of percentage of HIV diagnoses during the specified year attributed to persons who inject drugs (PWID) and heterosexual transmission risk groups compared to the percentage among MSM. The estimated number of persons with indications

for PrEP in the three major transmission risk groups (MSM, heterosexuals, PWID) in each jurisdiction are then summed to yield national estimates.

- Data availability: Data are published annually. Preliminary data are also available quarterly.
- Note: Prescriptions for PrEP or having indications for PrEP are not reportable conditions and therefore are not reported through the National HIV Surveillance System. Annual data will be used to measure progress.

Indicator 5: Increase linkage to care

- Definition:
    - ◇ Numerator: Number of persons aged ≥13 years with HIV diagnosed in a measurement year and who had ≥1 viral load (VL) or CD4 test ≤1 month after HIV diagnosis.
    - ◇ Denominator: Number of persons aged ≥13 years with HIV infection diagnosed during a measurement year.
- Baseline year: 2017
- Baseline result: 77.8%
- Target: By 2025, increase to 95%.
- Data source: National HIV Surveillance System (NHSS). NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.[2]
- Data availability: Data are published annually. Preliminary data are also available quarterly.
- Notes: Data are reported for jurisdictions with complete laboratory reporting of CD4 and viral load test results to CDC. The number of jurisdictions may vary each year. Provisional annual data (annual data with ≥12 months of reporting delay) will be used to measure progress.

Indicator 6: Increase viral suppression

- Definition:
    - ◇ Numerator: Number of persons aged ≥13 years living with diagnosed HIV and have a viral load test result <200 copies/mL at the most recent viral load test during a measurement year.
    - ◇ Denominator: Number of persons aged ≥13 years living with diagnosed HIV by the end of the year prior to the measurement year and alive at the end of the measurement year.
- Example: Denominator for 2019 viral suppression is the number of persons aged ≥13 years living with diagnosed HIV by the end of 2018 and alive at the end of 2019.
- Baseline year: 2017
- Baseline result: 63.1%
- Target: By 2025, increase to 95%.
- Data source: National HIV Surveillance System (NHSS). NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.[2]
- Data availability: Data are published annually.
- Note: Data are reported for jurisdictions with complete laboratory reporting of CD4 and viral load test results to CDC and with complete death ascertainment. The number of jurisdictions may vary each year.

Indicator 7: Decrease stigma

- Definition: The median score of a 10-item stigma scale, ranging from 0 (no stigma) to 100 (high stigma), measured among persons aged >18 years living with diagnosed HIV infection living in the United States and Puerto Rico.

- Note: The stigma scale was revised for the 2018 data collection cycle and includes three questions with a 12-month reference period to allow participants to provide experiences in a defined and more recent period of time for one domain of stigma (personalized stigma).
- Baseline year: 2018
- Baseline result: 31.2 median score
- Target: By 2025, decrease by 50%.
- Data source: Medical Monitoring Project (MMP). MMP is a cross-sectional, nationally representative, complex sample survey that assesses the behavioral and clinical characteristics of adults with diagnosed HIV infection in the United States. MMP also provides information on behaviors and clinical outcomes affecting the risk of HIV transmission, morbidity, and mortality. In 2015, MMP sampling and weighting methods were revised to include all adults with diagnosed HIV infection regardless of HIV care status.
- Data availability: Data are published annually.

Indicator 8: Reduce homelessness

- Definition:
  - ◇ Numerator: Number of persons aged ≥18 years living with diagnosed HIV in a measurement year and report having been homeless during the 12 months prior to interview. Homelessness is defined as living on the street, living in a shelter, living in a single-room-occupancy hotel, or living in a car.
  - ◇ Denominator: A sample of persons aged ≥18 years living with diagnosed HIV in a measurement year, as documented in the medical record.
- Baseline year: 2017
- Baseline result: 9.1%
- Target: By 2025, reduce by 50%.
- Data source: Medical Monitoring Project (MMP). MMP is a cross-sectional, nationally representative, complex sample survey that assesses the behavioral and clinical characteristics of adults with diagnosed HIV infection in the United States. MMP also provides information on behaviors and clinical outcomes affecting the risk of HIV transmission, morbidity, and mortality. In 2015, MMP sampling and weighting methods were revised to include all adults with diagnosed HIV infection regardless of HIV care status.
- Data availability: Data are published annually.

Indicator 9: Increase LGBTQ-supportive school policies and practices

- Definition: This indicator is the median percentage of secondary schools that are implementing at least four of seven school policies and practices that are known to improve health outcomes for both LGBTQ youth and all students: (1) having a Gay/Straight Alliance (GSA) or similar club, (2) identifying safe spaces, (3) prohibiting harassment based on sexual orientation or gender identity, (4) encouraging staff to attend professional development; (5) facilitating access to out-of-school health service providers, (6) facilitating access to out-of-school social and psychological service providers, and (7) providing LGBTQ-relevant curricula or supplementary materials.
- Baseline year: 2018
- Baseline result: 59.8%
- Targets: By 2025, increase the median percentage of secondary schools that are implementing at least four of seven LGBTQ-supportive policies and practices to 65% from a 2018 baseline of 59.8%. By 2030, increase the median percentage of secondary schools to 68.7%.

- Data source: CDC School Health Profiles. The School Health Profiles is a system of surveys assessing school health policies and practices in states, large urban school districts, and territories.
- Data availability: Data are published bi-annually.

Disparities Indicators

To monitor our progress in addressing HIV disparities, the viral suppression indicator is monitored for the following priority populations.

MSM

- Definition:
  - ◇ Numerator: Number of persons with male-to-male sexual contact (MSM) aged ≥13 years living with diagnosed HIV and have a viral load test result <200 copies/mL at the most recent viral load test during a measurement year.
  - ◇ Denominator: Number of persons with male-to-male sexual contact (MSM) aged ≥13 years living with diagnosed HIV by the end of the year prior to the measurement year and alive at the end of the measurement year.
- Baseline year: 2017
- Baseline result: 66.1%
- Target: By 2025, increase to 95%.
- Data source: National HIV Surveillance System (NHSS).[2] NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.
- Data availability: Data are published annually.
- Note: Data are reported for jurisdictions with complete laboratory reporting of CD4 and viral load test results and with complete death ascertainment. The number of jurisdictions may vary each year.

Black/African American MSM

- Definition:
  - ◇ Numerator: Number of Black/African American persons with male-to-male sexual contact (MSM) aged ≥13 years living with diagnosed HIV and have a viral load test result <200 copies/mL at the most recent viral load test during a measurement year.
  - ◇ Denominator: Number of Black/African American persons with male-to-male sexual contact (MSM) aged ≥13 years living with diagnosed HIV by the end of the year prior to the measurement year and alive at the end of the measurement year.
- Baseline year: 2017
- Baseline result: 58.4%
- Target: By 2025, increase to 95%.
- Data availability: Data are published annually.
- Data source: National HIV Surveillance System (NHSS).[2] NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.
- Note: Data are reported for jurisdictions with complete laboratory reporting of CD4 and viral load test results and with complete death ascertainment. The number of jurisdictions may vary each year.

Hispanic/Latino MSM

- Definition:
  - Numerator: Number of Hispanic/Latino persons with male-to-male sexual contact (MSM) aged ≥13 years living with diagnosed HIV and have a viral load test result <200 copies/mL at the most recent viral load test during a measurement year.
  - Denominator: Number of Hispanic/Latino persons with male-to-male sexual contact (MSM) aged ≥13 years living with diagnosed HIV by the end of the year prior to the measurement year and alive at the end of the measurement year.
- Baseline year: 2017
- Baseline result: 64.9%
- Target: By 2025, increase to 95%.
- Data source: National HIV Surveillance System (NHSS).[2] NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.
- Data availability: Data are published annually.
- Note: Data are reported for jurisdictions with complete laboratory reporting of CD4 and viral load test results and with complete death ascertainment. The number of jurisdictions may vary each year.

American Indian/Alaska Native MSM

- Definition:
  - Numerator: Number of American Indian/Alaska Native persons with male-to-male sexual contact (MSM) aged ≥13 years living with diagnosed HIV and have a viral load test result <200 copies/mL at the most recent viral load test during a measurement year.
  - Denominator: Number of American Indian/Alaska Native persons with male-to-male sexual contact (MSM) aged ≥13 years living with diagnosed HIV by the end of the year prior to the measurement year and alive at the end of the measurement year.
- Baseline year: 2017
- Baseline result: 67.3%
- Target: By 2025, increase to 95%.
- Data source: National HIV Surveillance System (NHSS).[2] NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.
- Data availability: Data are published annually.
- Note: Data are reported for jurisdictions with complete laboratory reporting of CD4 and viral load test results and with complete death ascertainment. The number of jurisdictions may vary each year.

Black Women

- Definition:
  - Numerator: Number of Black/African American females aged ≥13 years living with diagnosed HIV and have a viral load test result <200 copies/mL at the most recent viral load test during a measurement year.
  - Denominator: Number of Black/African American females aged ≥13 years living with diagnosed HIV by the end of the year prior to the measurement year and alive at the end of the measurement year.
- Baseline year: 2017
- Baseline result: 59.3%

- Target: By 2025, increase to 95%.
- Data source: National HIV Surveillance System (NHSS).[2] NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.
- Data availability: Data are published annually.
- Note: Data are reported for jurisdictions with complete laboratory reporting of CD4 and viral load test results and with complete death ascertainment. The number of jurisdictions may vary each year.

Transgender Women in HIV Medical Care

- Definition:
  - Numerator: Number of transgender women living with HIV ≥13 years who received from a Ryan White HIV/AIDS Provider at least one outpatient ambulatory health care (OAHC) visit and had at least one viral load test during the measurement year who was virally suppressed. Viral suppression was defined as the most recently reported HIV test result of <200 copies/mL.
  - Denominator: Number of transgender women living with HIV ≥13 years who received from a Ryan White HIV/AIDS Provider at least one outpatient ambulatory health care (OAHC) visit and had at least one viral load test during the measurement year.
- Baseline year: 2017
- Baseline result: 80.5%
- Target: By 2025, increase to 95%.
- Data source: Ryan White HIV/AIDS Program Services Report[5]
- Data availability: Data are published annually.

People Who Inject Drugs (PWID)

- Definition:
  - Numerator: Number of persons who inject drugs aged ≥13 years living with diagnosed HIV and have a viral load test result <200 copies/mL at the most recent viral load test during a measurement year.
  - Denominator: Number of persons who inject drugs aged ≥13 years living with diagnosed HIV by the end of the year prior to the measurement year and alive at the end of the measurement year.
- Baseline year: 2017
- Baseline result: 54.9%
- Target: By 2025, increase to 95%.
- Data source: National HIV Surveillance System (NHSS).[2] NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.
- Data availability: Data are published annually.
- Note: Data are reported for jurisdictions with complete laboratory reporting of CD4 and viral load test results and with complete death ascertainment. The number of jurisdictions may vary each year.

Youth 13–24 years

- Definition:
  - Numerator: Number of persons aged 13–24 years living with diagnosed HIV and have a viral load test result <200 copies/mL at the most recent viral load test during a measurement year.
  - Denominator: Number of persons aged 13–24 years living with diagnosed HIV by the end of the year prior to the measurement year and alive at the end of the measurement year.

- Baseline year: 2017
- Baseline result: 54.9%
- Target: By 2025, increase to 95%.
- Data source: National HIV Surveillance System (NHSS).[2] NHSS is the primary source for monitoring trends in HIV in the United States. It is the data source for incidence, diagnoses, and other HIV care continuum data.
- Note: Data are reported for jurisdictions with complete laboratory reporting of CD4 and viral load test results and with complete death ascertainment. The number of jurisdictions may vary each year.

Developmental Indicator—Quality of life for people with HIV

In addition, one key issue, quality of life for people with HIV, was designated as the subject for a "developmental indicator," meaning that data sources, measures, and targets will be identified, and progress monitored thereafter. Potential data sources and measures exist for this indicator, but further work must be done to assess them and craft the specifications for this developmental indicator. Working with parties and organizations, the federal government will develop an indicator.

APPENDIX B: ACRONYMS

AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy
CDC	Centers for Disease Control and Prevention (HHS)
COVID-19	coronavirus disease 2019
EHE	Ending the HIV Epidemic in the U.S.
FDA	Food and Drug Administration (HHS)
HHS	U.S. Department of Health and Human Services
HIV	human immunodeficiency virus
HOPWA	Housing Opportunities for Persons With AIDS
HRSA	Health Resources and Services Administration (HHS)
IHS	Indian Health Service (HHS)
MSM	men who have sex with men
NHAS	National HIV/AIDS Strategy
NIH	National Institutes of Health
OASH	Office of the Assistant Secretary for Health (HHS)
OIDP	Office of Infectious Disease and HIV/AIDS Policy (HHS)
ONAP	Office of National AIDS Policy (White House)
PEP	post-exposure prophylaxis
PrEP	pre-exposure prophylaxis
PWID	people who inject drugs
RWHAP	Ryan White HIV/AIDS Program (HRSA)
SAMHSA	Substance Abuse and Mental Health Services Administration (HHS)
SARS-CoV-2	severe acute respiratory syndrome coronavirus 2
SSP	syringe services program
STI	sexually transmitted infection
U=U	Undetectable = Untransmittable
USPSTF	U.S. Preventative Services Task Force

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