WE THE PEOPLE
A Black Plan to End HIV
Contents

4 Profiles in Black Excellence
5 List of Figures
6 Introduction to a Black Plan to End HIV
11 The Enduring Legacy of Anti-Black Racism
12 HIV and Black America
14 40 Years of Struggle: The History of the Response to HIV in Black America
17 The Quest to End HIV in the United States
17 A Black Plan to End HIV in America
23 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
35 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
43 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
55 Build the capacity and motivation of Black communities to be the change agents for ending HIV
57 Lessons from NYC’s Progress Toward Ending its HIV Epidemic
63 Toward Ending the HIV Epidemic: Implementing the We the People Vision and Framework
66 Notes
73 Black AIDS Institute

We The People
is a publication of the
Black AIDS Institute
1833 West Eighth Street
Los Angeles, California 90057-4257
213-353-3610, 213-989-0181 fax
info@BlackAIDS.org
www.BlackAIDS.org

© 2020 Black AIDS Institute.
All rights reserved.

The slogan “Our People, Our Problem, Our Solution” is a trademark of the
Black AIDS Institute.

Ver. 1.0

Views and opinions expressed in this publication are not necessarily those of the Black AIDS Institute, its partners, or the funders of this publication. Views, opinions and comments expressed by the participants are those of the particular individual speaking and do not necessarily represent the views and opinions of other participants or the Black AIDS Institute. Publication of the name or photograph of a person does not indicate the sexual orientation or HIV status of the person or necessarily constitute an endorsement of the Institute or its policies. Some photographs in this publication use professional models for illustrative purposes only.

We The People is designed for educational purposes only and is not engaged in rendering medical advice or professional services. The information provided through this publication should not be used for diagnosing or treating a health problem or a disease. It is not a substitute for professional care.

This report was made possible, in part, by the generous support of Janssen Pharmaceuticals. Additional support was provided by Gilead Sciences and amfAR.
Profiles in Black Excellence

13  Slavery’s impact on every facet of American life: The 1619 Project
20  Celebrating, Healing and Transforming Lives to Resist Transphobia
24  Using a Racial Justice Approach to Fight HIV
32  Grassroots Action to Fight HIV Among Black Women
40  Faith-Based Action to Combat Stigma and Promote HIV Prevention
52  Uniting Diverse Partners to Drive Change at the State and Local Level
60  Leveraging Love to Expand Healthcare and Rights for Trans People
64  Using Self-Love and Empowerment to Combat Homophobia
75  Promoting Black-Serving and Black-Led Community Organizations

List of Figures

16  Jurisdictions Prioritized in Ending the HIV Epidemic: A Plan for America
26  Status of State Laws Prohibiting Employment Discrimination Based on Sexual Orientation and Gender Identity
28  HIV Criminalization in the United States
29  Lifetime Likelihood of Imprisonment of U.S. Residents Born in 2001
44  Number of Uninsured and Uninsured Rate Among the Nonelderly Population, 2008-2017
45  Status of State Medicaid Expansion Decisions
47  Health Professional Shortage Areas: Primary Care, by County, 2019
Introduction to a Black Plan 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 at our disposal—including long-acting, injectable antiretrovirals for both treatment and prevention and a plausible future of a cure and vaccine.

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 godsend 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 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.
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.
We The People

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.

We The People

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—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.4 Even in the midst of record low unemployment, Black people are roughly twice as likely as whites to be out of a job.8

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.6 Infants born to Black women are more than twice as likely to die as those born to white women.8 Black people are 23% more likely than white people to die of heart disease,12% more likely to die of cancer, 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...
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. Black youth (ages 13-29 years) in 2010-2014 were 10.5 times more likely to be diagnosed with HIV than their white peers. 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.

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. 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. Among Black gay men ages 25-34, new HIV diagnoses increased by 40% from 2010 to 2016. 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. Around half of all trans people diagnosed with HIV live in the South. 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. Due to late HIV diagnosis and widespread barriers to healthcare access and utilization in the region, HIV-related mortality in the same Southern states is three times higher than among people living in states outside the region.

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. Yet the epidemic’s disproportionate impact in Black communities has often elicited so little response—from policy-makers, public health officials and even Black America itself.

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 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.”

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 journalists 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. 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?”

PROFILES IN BLACK EXCELLENCE

Slavery’s impact on every facet of American life: The 1619 Project
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 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 ten years, and basketball star Magic Johnson and Alvin Ailey, died of AIDS-related causes in the late 1980s. Spurred in part by the AIDS crisis, 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 continued to worsen. 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 prioritized 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 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

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 enough.”

The following year, spurred by new research findings that antiretroviral therapy reduces by 96% or more the risk of HIV transmission, 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. 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.

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., San Juan, Puerto Rico, and seven states with substantial rural epidemics (primarily in the South).

A Black Plan 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.

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 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 D.C., San Juan, Puerto Rico, and seven states with substantial rural epidemics (primarily in the South).
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 *End- ing 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 Plan 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 plan 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 plan, the Institute has pursued a people-centered approach to developing *We the People: A Black Plan 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 plan, 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 plan 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 plan for America as a whole—and specifically for Black America. The Black AIDS Institute lacks the capacity to implement this plan on its own, and it has no desire to, as the purpose of this plan 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.
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. For Williams, however, that was not an option.

“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/rials 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, our 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 woman, 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 lottering. 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.
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. The subordination of Black people extends across multiple domains—in housing, employment, criminal justice, sexual and reproductive rights, sexual expression, gender identity, and voting.

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 Democra-]izing Education as a two-part phenomenon that “voids Blackness of value while systematically marginalizing Black people and their issues.” Anti-Blackness is mani-]feated 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.)
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 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.”

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.”
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. 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

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.
We The People

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. 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 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.” Unfortunately, 21 states do not mandate sex education in schools. And 33 states do not require that any sex education provided to young people be medically accurate. In the South, only four states demand medical accuracy for sex education provided to young people.

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. 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.

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.
While Americans make up roughly 5% of the world’s population, the U.S. accounts for 21% of all prisoners.31 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 lows64, 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.43 However, in recent years, numerous states have taken steps to withhold or diminish Black people’s ability to exercise their constitutional voting rights.44 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 felony69, 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 civicly 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 account-
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 policy makers 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 away 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.”
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. Nationally, Black people are more likely than whites to have a diagnosis of post-traumatic stress disorder. In one primary care population in Washington D.C., 65% of Black patients were found to have experienced a traumatizing event. According to a 2019 study, the experience of discrimination is significantly associated with post-traumatic stress disorder among Black adults.

All too often, service providers treat trauma-ized 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. “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.

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. 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. Accordingly, mental health services need to be integrated across all HIV services. 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 the medically diagnosed HIV via injecting drug use. 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. 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.

Harm reduction strategies—a package of services that includes needle and syringe exchange, opioid substitution therapy and access to behavioral and biomedical health care—reduce the risks associated with drug use and are strongly recommended by public health authorities as a pillar of HIV services. 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. 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. 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. 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.
Reform immigration policies and practices

The number of Black immigrants to the U.S. has risen more than five-fold since 1980, now exceeding 4 million people, including more than 600,000 who are undocumented. Black immigrants are more likely than other immigrant groups to be U.S. citizens and to speak proficient English, and they are more likely than the U.S. population as a whole to have a college degree or higher. In many ways, the experience of Black immigrants to the U.S. has similarities with the experience of millions of Black Americans who made up the Great Migration in the 20th century. In moving in search of greater opportunities, Black immigrants have frequently been met with racism and exclusion from basic services—patterns that have only intensified with the wave of xenophobia that has swept over the country in recent years. Indeed, immigration rights advocates report that the effects of anti-immigration provisions are often felt most harshly by Black immigrants.

Immigrants who have yet to become U.S. citizens are nearly three times as likely (six times as likely among the undocumented) to be uninsured as Americans as a whole. Moreover, harsh proposed changes to immigrant policy (e.g., to take use of Medicaid and other assistance programs into account in assessing whether citizenship applicants risk becoming a “public charge”) risk increasing healthcare gaps by deterring people from seeking services they need.

As a nation of immigrants, America urgently needs to reimagine its immigration policies. Proposals to discriminate against immigration applications based on the applicant’s country of origin should be rejected. Similarly unacceptable are harsh applications of the public charge analysis for immigration eligibility. Culturally and linguistically appropriate services should be available for the diversity of America’s immigrants, and coercive detention and deportation proceedings (including but not limited to family separation) should be prohibited. All of these measures should be implemented in a manner that meets the needs of the African diaspora.

Increase awareness and prevention of violence through transformative and restorative justice

The experience of violence is all too common among Black people. Among Black women, nearly one in five will experience a sexual assault in their lifetime. Black children, adolescents and young adults are markedly more likely than white youth to experience homicide, aggravated assaults and injuries from fights. And while Black people account for 13% of the U.S. population, they represent 25% of those killed by police.

Numerous studies have linked the experience of violence and/or childhood trauma with an increased risk of HIV infection, especially among women. Among living with HIV, more than half have experienced intimate partner violence and nearly 40% experienced childhood sexual abuse—rates that are double those reported for women as a whole. A growing number of validated strategies have emerged to prevent violence. These include bystander education initiatives to equip individuals with the knowledge and skills to intervene safely and effectively to prevent and address violence. Roll-out of these evidence-based strategies should be prioritized, taking into account the full array of violence, including systemic violence, police abuse, gender-based and intimate partner violence, anti-trans violence and community-level violence. In addition, as the #Metoo movement reveals, grassroots activism has a pivotal role to play in increasing awareness and prevention of violence and other forms of abuse. She Safe, We Safe, an initiative led by BYP100, is a grassroots movement that aims to end gender-based violence in Black communities. Community-centered programs, such as those offered by the Black Emotional and Mental Health and Collective (BEAM) and the She Safe We Safe movement, urgently need to be expanded and fully resourced to promote emotional and mental health and wellness of Black communities and violence prevention within these communities.

Reduce poverty and promote the prosperity and economic development of Black communities

The gap in wealth between white and Black Americans is one of the most pernicious and persistent legacies of slavery. A key factor in the inter-generational disparities in wealth is the poor economic opportunities for Black men, which contribute to the transmission of poverty from one Black generation to the next. Over time, HIV in the U.S. has evolved to become an epidemic that is heavily concentrated in low-income communities. The lower an individual’s socioeconomic status, the greater the risk of having HIV. Poverty is not only associated with increases in behaviors that can lead to HIV transmission, but it also diminishes the ability of an HIV-affected household to undertake self-care or access essential health services.

Fighting poverty must go hand in hand with fighting HIV. To enable accelerated progress in reducing new HIV infections and HIV-associated deaths, major new investments are needed to increase employment in job-poor areas (including through targeted tax incentives) and provide training to build employable skills. And poverty must no longer be treated as a crime, underscoring the need to eliminate incarceration for court debts and prohibit police sweeps of homeless populations.
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] 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 Robinson, a key member of BTAN Melbourne. “We have 20 or more people who are active in the chapter, but none of them work full-time in HIV. BTAN Melbourne has 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.
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, unfeathered 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.\textsuperscript{104} Even with the Affordable Care Act (ACA) in place, 27.5 million Americans lack health coverage.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{108} Following the first year of implementation of the ACA, the uninsured rate among Black people living with HIV fell by one-third.\textsuperscript{109}
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.115

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 communities.

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

Source: Henry J. Kaiser Family Foundation

Status of State Medicaid Expansion Decisions

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. 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. These negative experiences reinforce the medical mistrust that is common in Black communities, 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.

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 humane 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. 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.

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. Focused capacity-building 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. 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. 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,
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 biomedically 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 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\textsuperscript{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\textsuperscript{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) in order to develop educational materials and hold trainings on HIV vaccine and biomedical prevention research advocacy across the South 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 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.
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
We The People

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. 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 with diagnosed HIV infection are receiving antiretroviral therapy, and 92% of those on treatment are virally suppressed. 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. The decline in new HIV diagnoses has been especially pronounced for Black New Yorkers—from 3,097 in 2001 to 919 in 2017.

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. 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.

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.

To replicate New York’s successful push to end its HIV epidemic, we will need to persuade state and local policymakers 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.

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 efforts should be required to enable EHE jurisdictions to follow in New York’s footsteps.

In 2001 to 2017, the annual number of new HIV diagnoses declined across New York City by nearly two-thirds. The decline in new HIV diagnoses has been especially pronounced for Black New Yorkers—from 3,097 in 2001 to 919 in 2017.

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. 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.

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.

To replicate New York’s successful push to end its HIV epidemic, we will need to persuade state and local policymakers 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.

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 efforts should be required to enable EHE jurisdictions to follow in New York’s footsteps.
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.

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.

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.
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.

“Lots 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,” Alyson 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,” Alyson 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.”
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 multifaceted 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 stakehold-

ers 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.”

PROFILES IN BLACK EXCELLENCE
100. Schemerhorn, C., Why the racial wealth gap persists, more than 150 year after emancipation, in Washington Post. 2019.
119. LaVeist, T. K., Nickerson, and J. Bowie, Attitudes about Racism, Medical Mistrust, and Satisfaction with Care among African American and White Cardiac Patients. Medical Care Research and Review, 2000. 57(1).
122. Chabria, A., California may soon push doctors and lawyers to confront their biases, in Los Angeles Times. 2019.
129. CDC. Addressing Chronic Disease through Community Health Workers: A Policy and Systems-Level Approach. 2015, Centers for Disease Control and Prevention: Atlanta.
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.

Throughout 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 community 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 resource 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.