

We the People: A Black Strategy to End the HIV Epidemic in the United States of America

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Abstract

The two previous United States presidential administrations implemented efforts to combat HIV/AIDS, recently leading to a plan to end this epidemic by 2030. Although the plan outlines a biomedical framework of key areas to address, it does not prioritize the core systemic and social issues that have caused the disease to devastate Black communities. The Black AIDS Institute (BAI) responded directly to this gap with "We the People: A Black Strategy to End HIV." BAI connected with Black community members across the country and conducted key informant interviews, held town hall meetings, and hosted a community forum in the U.S.

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Conference on AIDS. Based on this extensive community-level input, BAI, along with a diverse group of social justice partners, finalized the plan's strategic direction and recommendations. The efforts culminated in the "We the People" framework's four key pillars directly informing all of BAI's policy work, to include radically reimagining housing, health care, and criminalization systems that perpetuate the HIV/AIDS crisis among Black Americans. "We the People" outlines a clear path to engage policymakers and ensure all communities can effectively access and utilize the treatment and prevention advances that have the potential to soon end this epidemic.

Keywords: HIV/AIDS epidemic, Black HIV, HIV public policy, systemic oppression, equitable systems, we the people

Introduction

Since the initial days of HIV/AIDS, remarkable scientific advances have been made. Today's medicines help to prevent the transmission of HIV and reduce its progression. With medical adherence, many people living with HIV (PLWH) can expect lives as long as people who do not live with the virus (Cahill, & Valadéz, 2013), and risk of transmission is often $\leq 1\%$ (Centers for Disease Control and Prevention, 2021). The future of HIV biomedicine can plausibly include even better treatment and prevention modalities, as well as a vaccine and cure.

However, HIV continues to be a public health crisis in Black America. Constituting 13% of the United States population, Black Americans comprise $>40\%$ of PLWH, as well as just over 40% of new HIV diagnoses (Centers for Disease Control and Prevention, 2020). The disproportionate effects of HIV are especially apparent among Black gay and bisexual men, as approximately 1 out of every 2 Black gay/bisexual men is estimated to acquire HIV during his/their lifetime (Centers for Disease Control and Prevention, 2017). Of Black PLWH, 85% are aware of their status, but just under half are retained in care (Centers for Disease Control and Prevention, 2017). Black America's unique vulnerability to HIV is rooted in decades of structural oppression following centuries of chattel slavery; the oppression's resultant social and structural issues include poverty, anti-Black racism, homophobia, transphobia, housing and food instability, limited educational and employment opportunities, as well as a diminished quality of mental and physical health (Jeffries & Henny, 2019).

In 2010, the Obama administration established the first National HIV/AIDS strategy, which primarily sought to reduce new infections and deaths (White House Office of National AIDS Policy, 2015). The strategy placed focus on marginalized populations; however, it did not dive deeply into root causes, and the current state of HIV among these populations demonstrates that the plan did not work as anticipated.

In 2019, the Trump administration presented a plan to end HIV in the United States by 2030; Dr. Anthony Fauci then unveiled the rationale for this Ending the HIV Epidemic (EHE) plan that proposed additional funding and biomedical strategies (Fauci et al., 2019). The plan left out important information about intersectionality and stemmed from an administration whose political leaders often touted core features, including racism,

homophobia, and transphobia, that perpetuate the HIV crisis among Black Americans and other disenfranchised populations. While federal initiatives are welcome and federal resources are essential, solely addressing biomedicine will not impact the root causes of Black America's large HIV vulnerability.

The disproportionate impact of HIV on Black Americans is inseparable from historical and present-day anti-Black racism, and it is impossible to solely utilize treatment modalities to end the HIV epidemic without considering root causes for disproportionality. Accordingly, efforts to deliver the latest biomedical tools will fail to significantly impact populations in need if there is little to no consideration of the intersectionality of marginalized populations. The structural and social barriers constricting many Black Americans into poverty, low-quality education and healthcare, housing instability, unemployment, mass incarceration, and voter suppression are also perpetuating high rates of HIV and poor outcomes in Black communities. It is critical to address these systems-level determinants of HIV-related health and to increase access to, and utilization of, biomedical advances that may soon have the ability to eradicate the HIV/AIDS epidemic altogether.

Founded in 1999 as the United States' only unapologetically Black HIV "think and do" tank, the Black AIDS Institute (BAI) is uniquely poised to respond to gaps within national HIV strategies. With this research, BAI seeks to examine ways in which governmental agencies, community organizations, other institutions, and communities themselves can all focus resources and efforts on upstream determinants of health to effect the largest change on downstream incidence and prevalence of HIV among Black Americans.

Methods

Participants

Participant recruitment was conducted via flyer distribution and notifications within universities, BAI's treatment advocacy network, newspapers, webinars, local health departments, and community-based organizations. From this recruitment effort, 20 key informants and 124 community members from across the United States were invited and consented to participate.

Variables

A semi-structured focus group question guide was created, encouraging storytelling of experiences regarding the HIV workforce, living with HIV, and challenges and opportunities to address the HIV epidemic in Black America.

Research Design

This qualitative study used phenomenology and an inductive approach, with data obtained via community town halls and a focus group.

Procedures

BAI President and CEO Raniyah Copeland convened a meeting with organizational leadership following the Trump administration's February 2019 announced plan to end the HIV/AIDS epidemic. The BAI team acknowledged the federal administration's plan only included a biomedical, location-based approach; further, divisions arising from politically-encouraged racism, homophobia, and transphobia did not create an appropriate environment to effectively eradicate HIV in all American populations, particularly Black communities. Thus, this first meeting served to coordinate a process for assessment and response to the federal plan, and BAI immediately set out to obtain community input.

BAI pursued a community-centered approach in the design of its working framework, "We the People: A Black Strategy to End HIV" (WTP). Consistent with its name, "We the People" was developed through an extensive outreach and consultation process with Black communities, stakeholders, and experts across the country. To inform the strategy for WTP, BAI conducted key informant interviews, held town hall meetings in three southern states, and hosted a community forum at the United States Conference on AIDS (USCA). The Black Treatment Advocates Network (BTAN) was pivotal in linking BAI to community members and experts who could inform the framework. BTAN is BAI's national network of HIV/AIDS stakeholders including service providers, community members and leaders, educators, and PLWH, all of whom mobilize Black communities across the country to confront HIV.

Between February and August 2019, BAI planned and hosted in-person town hall conversations with community members in Houston, TX (n=58); Montgomery, AL (n=22); and Natchez, MS (n=44). Following warm-up introductory conversation, participants were asked open-ended questions to allow free response. Community members provided insight on key action steps and overall strategies to include within a Black plan to end HIV. Field notes were taken during each event and later analyzed by BAI staff and a project consultant to form the initial framework. This initial plan was then piloted for input in September 2019 as "Ending the Epidemic: Our Time for Our Solution" at the USCA and updated accordingly.

In December 2019, 20 key informants joined BAI in Los Angeles for intensive, in-person data collection in the form of a focus group. These key informants included HIV clinicians, community advocates, state and local representatives, PLWH, community organization representatives, members of Black media, human and civil rights organization leaders, as well as criminal justice activists. Similar to the town halls, participants were asked open-ended questions and allowed to respond freely. Field notes were taken and analyzed by BAI staff and a project consultant. For the focus groups, questions also revolved around the plan derived from the town halls and USCA, and the key informants were asked to provide detailed feedback.

The qualitative data from all of the collection events were analyzed for themes, culminating in the clustering of four pillars and supporting components of the final plan. The

framework was promoted nationally in February 2020 and February 2021 to coincide with National Black HIV Awareness Day. During the year between, presentations to the Black community and HIV workforce were conducted. These presentations were carried out through the BTAN and occurred virtually, due to constraints from the Coronavirus Disease 2019 (COVID-19) pandemic.

Results

The finalized “We the People” framework rests on four pillars of action: 1) Dismantle anti-Black practices, systems, and institutions that endanger the health and wellbeing 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; and 4) Build the capacity and motivation of Black communities to be the change agents for ending HIV. Each pillar includes specific recommendations, interwoven with one another and informed by community members, social justice advocates, and HIV workforce experts.

Pillar One: 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

HIV must be addressed as a racial and social justice issue. To dismantle anti-Black entities, local, state, and national anti-racism and social justice coalitions must be established. These situate HIV within a broader context of human rights. Some national movements, such as the creation of the HIV Racial Justice Now coalition, are visible; yet, overall, the efforts remain few, under-resourced, and inadequately mainstreamed across the HIV response.

At the state and local levels, decision-makers must move beyond siloed work, adopting nontraditional and multidimensional strategies for collective impact in dismantling anti-Black institutions, policies, and structural norms. If national, state, and local entities fully embrace HIV as an “upstream” racial and social justice issue, then “downstream” improvement of health outcomes and health equity will be achieved.

BAI tackles national, state, and local engagement and mobilization through the Institute’s flagship BTAN chapters and affiliates, most of which operate in priority EHE jurisdictions. The network currently connects 26 local grassroots chapters and affiliates across 15 states, offering a unique vehicle for assembling broad, multi-sectoral coalitions that center the HIV fight within the broader push for racial and social justice.

Mobilize Black Communities, Allies, and Officials to Reform Impeding Laws and Policies

Removing obstacles to an effective HIV response requires action at the federal, state, and local levels. It is critical to enact laws that recognize the diversity of Blackness and gender identity, as well as prohibit discrimination based on sexual orientation and implement gender-affirming laws, policies, and practices. These laws help create a climate that effectively stifles discrimination against people who identify as Black and/or LGBTQIA+. For urban areas to be more affirming of the LGBTQIA+ community, city ordinances can offer an effective avenue for enacting anti-discrimination and other human rights provisions. However, states can currently act to “preempt” cities’ or counties’ rights to legislate on particular issues, such as anti-discrimination. If this preemption grows in popularity among state legislators, local efforts to pass human rights ordinances will need to cultivate champions and build support among state legislators to reverse these preemption efforts.

Relatedly, states may enact counterproductive laws that criminalize HIV exposure, non-disclosure, and/or transmission in a misguided effort to prevent new HIV infections. This existence of HIV criminalization does not need to be permanent. Instead, states can repeal or reform such laws and commit to grounding their HIV prevention approaches within sound science and evidence-based non-discrimination principles.

Further, on a national level, America’s prison industrial complex and apparent addiction to mass incarceration are commonly understood to be part of a clear and painful legacy of slavery and racism, as the weight of mass incarceration in the United States is known to be largely and disproportionately borne by Black communities (Pettit & Gutierrez, 2018). People living with HIV who undergo incarceration are at great risk of discontinuing critical care, both during that incarceration and upon release (Milloy et al., 2014). Thus, if Black Americans are incarcerated and living with HIV at disproportionately high rates independently, then a logical deduction would be that incarcerated Black PLWH risk continuity of care and negative health outcomes as a result of the disruption caused by a systemically oppressive criminal justice system. A general bipartisan consensus has emerged on the need to reform America’s approach to mass incarceration, whether for moral and/or financial reasons; however, the needed concrete action to dismantle the country’s counterproductive approach to policing and prison has yet to be taken. The United States must eliminate: its costly and ineffective system of mass incarceration, the immunity of law enforcement agents abusive toward Black Americans (e.g., those who are sex workers or misuse substances), and inequitable practices, like cash bail. Simultaneously, concentrated efforts should include improving HIV services for people currently and formerly incarcerated, as well as including care and support for the citizens’ reentry into the community.

Advance Accountability Through State and Local Policy Scorecards

HIV racial and social justice coalitions at the state and local levels should create scorecards to monitor the success of their governments in creating a policy environment that supports an effective HIV response. Not only will these scorecards increase the accountability

of state and local decision-makers, but they will also provide evidence to diverse audiences as to how HIV outcomes are associated with progress on broader racial and social justice issues.

Increase Black Voter Turnout to Advance Critical Policies and Systems

Increased Black voter turnout is vital to elevating the number of elected officials who advance policies and systems critical to Black Americans' wellbeing. The vote should be the most effective means of ushering in the legal and policy reform needed to remove the structural disadvantages that Black communities face. However, when states take steps to curtail Black Americans' ability to exercise their constitutional voting rights, this reform is difficult to realize. States can diminish voting rights by implementing voter identification requirements, restricting opportunities to register to vote, closing voting spaces, or reducing early voting. Further, racial gerrymandering practices can also weaken Black voters' political power. These blatantly unfair and unconstitutional efforts to lessen Black voters have generated an array of initiatives by Black leaders, such as voting rights activist Stacey Abrams and Former United States Attorney General Eric Holder, to fight voter suppression. As evidenced in the way Black people, particularly women, galvanized to support then-candidate Joe Biden in the Democratic primary and presidential elections of 2020, Black communities have the ability to become self-empowered and influence the way they are governed. Further, while working to roll back voter restrictions, these same communities should intensify efforts to register voters and promote consistently robust voter turnout.

Ensure Unfettered Access to Comprehensive Sexual and Reproductive Health Services and Education

It is a person's fundamental human right to make autonomous decisions regarding their own sexual and reproductive health. This right demands that everyone possesses access to medically accurate and person-centered education and counseling, contraception, family planning, and abortion services. Patient-led care is the standard and not the exception. However, a growing number of states have taken steps to undermine the federal guarantee of contraception access in the Affordable Care Act (ACA) and to restrict access to abortion services.

Relatedly, HIV prevention begins as early as childhood sex education. Equipping young people with the skills they need to avoid HIV and to live full and healthy lives if they acquire HIV requires investments in comprehensive, culturally-relevant, and medically-accurate sex education. This education must embrace the myriad of gender identities and the diversity of sexual attraction and expression.

Pillar Two: Provide Resources and Services that Address the Fullness, Richness, Potential, and Expertise of Black People and Mitigate Social and Structural Factors that Worsen Health Outcomes in Black Communities

In the United States, the HIV response has primarily focused on the biomedical advances that can prevent HIV infections, as well as HIV-related illness and death. Given the

multiple social factors that increase Black communities' vulnerability to HIV and affect Black Americans' ability to access and benefit from biomedical services, healthcare for Black people affected by HIV needs to be holistic and personalized in its approach. A person's ability to effectively utilize HIV biomedicine is inevitably influenced by social factors, such as whether they have food security, stable housing, protection from violence, and positive mental health.

Ensure Effective Support Services

Holistic and integrated services can effectively address the lived realities of Black people and meet the needs and expectations of Black communities. Support service professionals must be prepared to provide the culturally-relevant, person-centered services that prevent HIV infection or optimize the wellness of PLWH. Here, cultural relevance includes the integration of trauma-informed practice. Oftentimes, service providers appear to view traumatized clients as "difficult" or "problematic." Instead, it is important to understand the influence that traumatic experiences, whether in childhood or adulthood, have on a person's reception, acceptance, and adherence to support. An individual with a background of trauma may not participate as a partner in HIV service delivery in the way that a provider generally expects; thus, it is critical for the provider to avoid bias and assumptions about how clients participate in their own care. Rather than blame or negatively label clients, service providers and the systems they navigate must prepare appropriate and individualized responses to trauma. Accordingly, resources that integrate peer recovery coaching, peer mentors, community clubhouses, and other person-centered approaches are imperative for the overall health, wellness, and motivation of individuals living with HIV.

Additionally, funding for HIV services needs to include resources for mental health care, to include traditional and nontraditional self-care, positive coping practices, and overall wellness. Positive mental health and wellness are vital to individuals successfully navigating the intersectional layers that accompany preventing, or living with, HIV. Though service providers are pivotal in managing HIV, self-care is equally important for such a chronic condition. Peer-based, community approaches empower, support, and mobilize PLWH; these strategies should be prioritized in the allocation of resources for ending the epidemic.

Similarly, because substance misuse can increase the risk of a person acquiring HIV (Pellowski et al., 2013), as well as reduce the capacity of PLWH to consistently access and engage in HIV care (Kuchinad et al., 2016), an additional layer of mental health support involves integrating harm reduction efforts into all HIV services and promoting evidence-based harm reduction initiatives throughout the Black community. Strategies in the form of needle and syringe exchange services, opioid substitution therapy, and access to behavioral and medical healthcare are all ways to incorporate harm reduction. However, implementing harm reduction strategies is hampered by issues like community stigma and funding restraints, the latter of which can include federal and state prohibitions, as well as siloed funding constraints that separate HIV and substance use treatment services. Overcoming these barriers is essential to addressing the layered health and social needs of people who misuse substances and also are affected by HIV.

Of particular note, certain segments of Black America receive even smaller amounts of elevation and culturally-relevant support services in the field of HIV prevention and treatment. In exemplar, Black cis women are often dismissed, or forgotten altogether, as a population that requires HIV services. Engagement and support are needed to ensure that marginalized communities like these and others within Black America are not overlooked and all have tailored service options.

All in all, achieving comprehensive services demands awareness and action not only at the service provider level but also among governments, as siloed systems and a lack of sufficient and relevant funding are important reasons why these services are so seldom integrated. Social and structural approaches that increase equity in services and empower Black communities are vital to progressing toward the HIV epidemic's end. Few of these socially and structurally-minded services are likely to succeed without the dismantling of America's oppressive systems, to include mass incarceration, education, health care, and housing. Inequitable systems significantly affect service access and utilization for Black families and communities across the country.

Promote Prosperity and Economic Development in Black Communities

Poverty is commonly associated with increases in behaviors that can lead to HIV transmission, but it also reduces the ability of those impacted by HIV to access critical health services (Pellowski et al., 2013). The fight against poverty must coincide with the fight against HIV. New funding investments are needed to accelerate the reduction of HIV incidence and HIV-associated deaths. These investments can increase employment through targeted tax incentives and provide professional development training to build workforce skills. Further, poverty is not a crime, and the United States must eliminate cash bail, incarceration for court-related debts, and police sweeps of homeless populations.

Further, housing insecurity and homelessness make achieving and sustaining viral suppression extremely difficult and, depending on circumstances, even impossible (Aidala et al., 2016). The outcomes from lacking a stable home are interconnected with other social determinants that heavily influence the health of a person living with HIV (Aidala et al., 2016). A federally-led effort to expand housing access and ensure linkage to housing assistance within HIV services is urgently needed, with triaging in the most affected cities and states.

Utilize Transformative and Restorative Justice Services to Improve Violence Prevention

The experience of violence is rooted in structural inequity and is all too common among Black Americans. Validated, evidence-based strategies to prevent violence should be prioritized, accounting for systemic violence, police abuse, gender-based and intimate partner violence, anti-trans violence and community-level violence. Further, as grassroots initiatives like the #MeToo and #SayHerName movements display (Valdivia, 2019), activism has a crucial role in raising public awareness and in preventing violence.

Reform Immigration Policies and Practices

Like millions of Black Americans who constituted the Great Migration from the United States South to the Midwest in the 20th century (Gould, 1991), Black immigrants are frequently targets of “othering” and excluded from basic human services. This pattern of xenophobia has only been intensified with politically-related rhetoric across the country in recent years. Further, proposed changes to immigrant-related policy (e.g., to leverage usage of Medicaid and other assistance programs against citizenship applicants) risk increasing healthcare disparities.

America, the “melting pot” nation of immigrants, must reimagine its immigration policies and resources, and any proposed legislation to discriminate against citizenship applications, based on the applicant’s country of origin or usage of human services should be rejected. Instead, culturally and linguistically relevant services should be available to meet the diversity of America’s immigrants, and dehumanizing detention and deportation processes (including family separation) should be clearly prohibited. These inclusive efforts, should they be implemented, would help meet the needs of the African diaspora and American immigrants, overall.

Pillar Three: 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

Even though advances in biomedicine have provided a real possibility to end the epidemic, we can only realize the full potential of these developments if everyone who needs them is able to use them. Putting these powerful medical tools to use involves two critical steps. First, to have people benefit from this biomedicine means that they must also have unhindered access to affordable healthcare services. Second, alongside access, people who need these biomedical tools require the knowledge and personalized care to effectively and consistently utilize the healthcare services that will deliver the tools.

Ensure a Healthcare System Equipped for High-quality Services Among All Black Americans

Access to high quality, affordable healthcare is a basic human right. This right is one that the United States consistently denies to millions of its people. The United States needs to build upon the Affordable Care Act to achieve universal health coverage, already realized in other major industrialized countries (Vladeck, 2003). There are multiple pathways to achieve this universal coverage; however, one commonality is that, without it, marginalized populations do not have the resources needed to live fully well lives.

However, until the vision for universal health coverage is realized in the United States, all states must expand Medicaid coverage. This ACA-allowed effort fills a gap that, otherwise,

leaves millions of vulnerable people without access to affordable health services (Obama, 2016). Any state that has yet to expand Medicaid must enact steps to do so immediately, and that state's political atmosphere should hold no bearing over the outcome of this expansion.

In addition to expanding health coverage, further policy steps are essential in enhancing the affordability and accessibility of healthcare products. The costs associated with purchasing medication and other pharmaceutical products can only be driven down with policy reform. The more cost-effective it is to purchase pre-exposure prophylaxis (PrEP), for example, the more likely it will be for a person to utilize it (Koechlin et al., 2017). The more a person is likely to utilize PrEP, the lesser instances of HIV transmission are likely to occur. Further, reducing the costs of HIV-related health products is not the only necessity. Instead, it is vital to lower prices for all medical products, as any costly medication can negatively impact individual budgets and influence a person's ability and likelihood of engaging in consistent HIV prevention and treatment.

Further, all stakeholders and interested parties should hold local and state governments accountable for a health system that perpetuates high HIV rates. One such area of advocacy includes encouraging the federal government to require, as a condition for receiving EHE funding, that each EHE jurisdiction conducts regular surveillance of key demographics and HIV-related health outcomes (e.g., new HIV diagnoses, AIDS-related deaths, HIV viral suppression, etc.). Jurisdictions that show racial/ethnic disparities in HIV outcomes should be required to establish a corrective action plan to address these gaps, in order to maintain eligibility for further EHE funding. The federal government should provide capacity-building support and incentivize providers to utilize collected data in improving their service delivery processes' performance and equity.

Lastly, rural counties, particularly in the South where Black America's HIV epidemic is heavily concentrated (Reif et al., 2017), must address hospital closures and any shortage of primary care services, in order to reduce mortality. Strategies to address these closures and shortages can include increased usage of telemedicine and the creation of smaller health centers to deliver health services in areas where hospitals are no longer viable.

Overcome Healthcare Utilization Barriers with Support for Black Experts, Efficient Clinical Environments, and Health Education

As a society, we must identify, understand, and address the factors that affect people's utilization of healthcare services. In many Black communities, for example, routine use of health services, especially for preventive care, is typically uncommon; this underscores the importance of developing new community norms for seeking care. New and significant investments in implementation science, led by Black researchers, must be made to identify strategies to increase HIV-related access and utilization of services, as well as improve health outcomes in Black communities. Black researchers have lived experience and an unmatched motivation to help increase knowledge in addressing the health needs of Black communities. Accordingly, these scientists are often best equipped to build strong relationships with Black community

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organizations, leading to research that not only informs the community but is also informed by the community. Specific, scientific efforts by Black researchers are vital in examining and addressing Black community perceptions about HIV services and biomedical technologies.

In addition to increasing the amount of Black researcher-led science, academic institutions should be incentivized to increase the number of Black enrollees and recipients of clinical degrees (e.g., MDs, RNs, NPs). Steps should also be taken to support Black students seeking education, training, and certification as healthcare professionals; such steps could include student loan relief and personalized outreach initiatives. Oftentimes, Black people encounter the healthcare system and do not see providers who look like them or fully understand their cultural background. Sharing a cultural identity with one's provider is important for many Black Americans to help alleviate stressors related to medical mistrust and a long history of racism and abuse in medical and public health practice (Wells & Gowda, 2020). Medical mistrust negatively impacts Black Americans' ability to seek necessary health care and can lead to further health deterioration, poor prognosis, and missed opportunities for intervention (Wells & Gowda, 2020). Drawn from the communities they serve, an increase in community health workers and other clinical professionals can help a health center overcome the effects of the long-standing medical mistrust in many Black communities.

Additionally, clinical environments that function inefficiently can discourage individuals from seeking the services they need. Thus, it is important to standardize clinic operations that create affirming spaces for Black clients. For example, Black patients who experience significantly longer waiting times for health services than White patients will likely not continue engaging in care at that location, if at all. Focused capacity-building assistance should be provided to help clinics function with more efficiency and compassion. Accordingly, healthcare professionals should be encouraged and/or required to use each client-provider interaction to provide in-depth support, such as inquiring about treatment adherence and associated barriers whenever a prescription is filled. All HIV service providers should have the knowledge and ability to deliver culturally humble and appropriate services to individuals of all racial and ethnic backgrounds. Legislation should mandate regular implicit bias and anti-racism trainings for healthcare professionals in health departments and clinical settings.

Further, if Black people do not possess strong scientific literacy, they may be less likely to assess their risk for HIV acquisition, learn their HIV status, adhere to prescribed treatment regimens, and remain engaged in care (Swenson et al., 2010). Thus, HIV science and treatment literacy must be increased in Black communities, through leveraging advertisement campaigns, social media, and the integration of HIV-related narratives in entertainment and other media platforms. This literacy support is necessary to build the capacity of Black consumers, so that they can serve as competent decision-making partners in their own health care. Community education programs are needed to raise 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 a culturally-relevant manner. To help overcome PrEP-related stigma, delivery channels outside of LGBTQIA+ and HIV-branded sites should be developed.

Relatedly, clinical trials and other work are well underway to develop a preventive vaccine and, ultimately, a cure for HIV. It is plausible that upcoming long-acting antiretrovirals could expand treatment and prevention options and potentially improve treatment adherence rates. However, work is needed now to prepare and educate communities and healthcare systems about any new approach and address concerns, in order to facilitate rapid uptake and positive outcomes for those who desire the treatment. In exemplar, to engage Black communities in prevention and vaccine research and to help prepare them for future prevention breakthroughs, BAI holds a formalized collaboration with the HIV Vaccine Trials Network (HVTN) to develop educational materials and trainings on HIV vaccine and prevention research in areas where HVTN clinical trials are being conducted.

Pillar Four: Build the Capacity and Motivation of Black Communities to be the Change Agents for Ending HIV

Since its founding, BAI's motto has been, "Our People, Our Problem, Our Solution." The Institute recognizes the central role that communities play in addressing complicated health challenges within themselves. If we hope to end the HIV epidemic, a crisis greatly present in Black communities, then Black Americans will need to lead the efforts. This empowerment and leadership demand substantial ownership of the HIV/AIDS fight in Black communities, as well as significant, new resources to support related community-centered efforts.

Generate Broad, Enthusiastic Ownership in Black Communities of the Fight to End HIV

Among its achievements, BAI takes great pride in its work supporting Black organizations and institutions in the development and implementation of community-driven, strategic HIV plans. However, this community leadership has never shown proportionality with the severity of the HIV crisis in Black America; not enough Black organizations and institutions have taken up the mantle to fight HIV. In fact, the concept of prioritizing HIV and its impact on Black Americans is seemingly discussed less each year in newspapers, magazines, the internet, the church pulpit, or among Black celebrities and opinion leaders. To end the HIV epidemic in Black America, we must re-energize our HIV champions and develop relationships with new partners in Black communities. Each aspect of Black America must take part in fighting HIV; this includes elected offices, faith-based organizations, historically Black colleges and universities, civic and fraternal organizations, Black media, Black celebrities, and everyday people who are concerned and desire to make positive change. To renew this HIV coalition, consistent engagement of these influential segments must occur, and HIV must be properly categorized as the racial and social justice issue it is.

With the great influx of social media, we now have new avenues to engage and mobilize Black Americans in an exciting manner. Black people are leveraging social media in activist efforts across the country, and now is the time to make HIV an activism issue once again, but in this new era centered on advocating for the complete wellbeing of Black people. As we work to refocus the attention of Black America on the HIV fight, we should also take steps

to normalize HIV as a health condition like many others, as well as reduce related stigma and concentrate attention on HIV testing and accessing prevention and treatment services. Further, within Black families and communities, we need to engage in intergenerational conversations that move toward a real culture change and openly address the fullness, wholeness, and diversity of Black Americans. Across all of our efforts to reignite Black communities' drive to eliminate the HIV epidemic, we must promote the voices and stories of Black PLWH, to include young leaders, people who identify as LGBTQIA+, sex workers, and people who were formerly incarcerated.

Allocate Sufficient Financial Resources for Black Communities to Lead Efforts to End HIV

An influx of new EHE funding, particularly from the Biden Administration, while welcome, should be understood only as a “down payment” on the planning and implementation resources that will be needed to end HIV. To truly end HIV and tackle the aforementioned systemic and structural issues, a substantial amount of additional funding is required, particularly in EHE jurisdictions where a comparatively limited tax base exists. EHE financial resources need to be directed toward communities of color, particularly as EHE funding borrows heavily from the Minority AIDS Initiative (<https://www.hiv.gov/federal-response/smaif/overview>).

Specifically, because of the HIV disproportionality in Black communities, by 2025, at least 60% of EHE funding should be earmarked for Black-led organizations. That is, these organizations are where Black Americans comprise the highest levels of primarily leadership (e.g., chief executive officer and executive director) and overall governance (e.g., board of directors, senior leadership team). In these next four years, the federal government should move toward this 60% earmark by using the funding for the large, Black-serving (but not Black-led) organizations to intimately collaborate with Black-led organizations in building necessary and sustainable infrastructure (e.g., processes and networks for grant-writing, donor engagement, human resources, finance management, administration, etc.). These intimate collaborations would serve as a “bridge,” with funding gradually and fully shifting to the Black-led organizations between years 1 and 4. These infrastructure-building contracts should be performance-based and should include clear milestones toward the empowerment and self-sufficiency of Black-led organizations to lead efforts to end the HIV epidemic. Further, as the federal government's EHE plan envisions a key role for federally qualified health centers (FQHCs) in reaching the most vulnerable populations, FQHCs must be expanded and diversified to include more smaller, Black-led organizations.

Focused investments across the public and private sector and toward Black leadership development are required to appropriately address the breadth of the needed HIV response. For example, in reimagining funding for Black-led organizations and initiatives in the HIV response, foundations and pharmaceutical/biotech companies should prioritize new funds, with the pharmaceutical and biotech companies earmarking a percentage of their profits for unrestricted granting in these efforts. These investments should ensure that Black-led and Black-serving organizations are prepared to optimize their performance to improve their communities' HIV

and broader health outcomes. While energy and commitment within grassroots efforts will remain vital to the Black response to HIV, it is essential to move beyond unpaid volunteerism and low paid work as the primary sources, or the backbone, of much of the response. Alternatively, strong fiscal pathways are essential to building the sustainable community infrastructure that is needed.

All told, elected officials and community leaders must engage Black community members and each other in EHE planning and implementation. Further, all agencies and organizations that receive federal EHE funding must have clear and significant processes in place to receive culturally-based feedback from Black communities; the processes could be in the form of recurrent community town halls and evaluations. These agencies and organizations must also utilize the information obtained through these community processes to inform and guide service delivery.

Discussion

The approach detailed here, while ambitious, is derived from a background of scientific evidence, as well as over 40 years of experience among BAI's staff, expert affiliates, and community partners working in the fight against the HIV/AIDS epidemic. For more than 20 of those years, BAI itself has served as the only national Black HIV "think and do" tank and supports the findings presented. To some, the idea of implementing this framework and encountering inevitable challenges or setbacks may be daunting. In fact, the HIV crisis is a complex and multifaceted problem; there will be no simple solution. On the contrary, the real solutions are layered and intricately intertwined with one another. Thus, if Americans desire to eradicate the HIV/AIDS epidemic, we must address the structural and social challenges that increase vulnerability to HIV, as well as hinder people's ability to access and benefit from valuable and effective biomedical tools. The "We the People" framework reflects this complexity, where several pillar components are interrelated and less distinct from pillar to pillar; addressing them would heavily advance the major solutions that the four pillars identify. Ultimately, because this crisis is so complex and disproportionately prevalent in Black communities, efforts must be driven by the lived experience and energetic leadership of Black Americans, with support from all levels of government and industry expertise.

Implementing the We the People Vision and Framework

"We the People" is a plan beyond the capacity of any single organization or agency. Black leaders, organizations, grassroots activists, and diverse stakeholders can use this set of strategies to restructure their fight against HIV and to prioritize their contributions toward ending the epidemic. The Black AIDS institute has committed to reorienting all of its work toward implementing this framework, as well as monitoring and regularly reporting on progress.

Over the past year, BAI has worked with its BTAN and other partners across the country to host WTP-related community town halls and meetings to develop jurisdiction-specific recommendations to end the HIV epidemic within these communities. BAI has

also leveraged the WTP framework in working to support focused efforts to move key suggestions from local communities forward, culminating in the creation of implementation recommendations for the federal, state, and local levels.

Governmental Implementation of the “We the People” Framework

Recommended priorities at the national level center on expanding access to, and financial support for, HIV prevention and treatment modalities. Access to PrEP and other prevention methods must be increased, and information campaigns should be run to educate the public. Specifically, PrEP services should be prioritized for segments of the Black American population not often elevated, including Black cisgender women (Sophus & Mitchell, 2020). Support for treatment modalities can include the monthly injectable regimen recently approved by the Food and Drug Administration (U.S. Food and Drug Administration, 2021). Further, the federal government must prioritize the Undetectable=Untransmittable (U=U) “treatment as prevention” ideology as the target for all HIV-related programs that serve Black Americans.

Additionally, the federal government must acknowledge the impact that generations of racism and anti-Black policies have had on medical mistrust and health disparities. Because racism is, in fact, a public health emergency (Centers for Disease Control and Prevention, 2021), the federal government must reevaluate priority public health and HIV programs to include the race-related experiences of Black Americans. Stigmas against Black and LGBTQIA+ people, as well as against HIV, must be introduced as national behavioral indicators and measured across HIV programs. Further, funding for Black-centric HIV programming and outreach must be prioritized, and the federal government must actively work to ensure a representative percentage of Black Americans are included in clinical trials for HIV, sexually transmitted infections (STIs), and COVID-19.

Both federal and state governments must prioritize issues that are currently, and unnecessarily, stigmatized and politicized. Voting access, particularly across southern states where many Black Americans live and are heavily affected by HIV, must be expanded and uncomplicated. Additionally, comprehensive sexual health education, including LGBTQIA+ awareness and stigma reduction, should be guaranteed to all young people. Further, federal and state governments need to ensure that people living in states without expanded Medicaid eligibility are able to access necessary care, and new funding should be provided to support and incentivize states that expand Medicaid eligibility.

Across all levels of government, Black Americans should comprise the majority of HIV decision-making leadership, with the remaining leaders being installed following input from Black Americans. Additionally, Black health experts and clinical researchers at all career development stages must be elevated and provided growth opportunities in leadership spaces, as well as spheres of program management and budgetary control. Federal, state, and local governments should partner with Black-led training and capacity building programs to increase the culturally-relevant knowledge of the HIV workforce. These governments should also invest in marketing and community-led programming that centers Black queer, non-binary, and

PLWH-relevant resources and experiences; they should also prioritize county/neighborhood partnership-building upon Black-centric initiatives that are led by individuals who represent the local community. Finally, federal, state, and local governments should increase policy reform and investments in affordable housing to expand access for everyone, particularly PLWH and homeless LBGTWIA+ youth.

Limitations and Considerations

As with many other efforts to assess and act upon structural and social determinants of health, this research is subject to several limitations. While participants from diverse disciplines, lived experiences, and backgrounds provided feedback in all of the community and expert forums, selection bias could be present. Black Americans are not monolithic, and the participants who gave feedback may not entirely represent the views, knowledge, or even the geographic scope of every Black person in the HIV workforce or living with HIV; methods could have been bolstered with additional town hall meetings across more states. Additionally, the techniques used to collect the data were qualitative in nature and did not use standardized surveys; this could have contributed to a limited ability to conduct a thorough data analysis, and future research may warrant either a quantitative approach or a more formalized qualitative approach. Further, data for this research was collected during a transition period for BAI, whereby the new leadership was becoming established and navigating new organizational processes; thus, time constraints in balancing this research with a new organizational structure could have played some role.

Large-scale change, such as that proposed in WTP, occurs in multiple domains, and no one individual or organizational entity can accomplish everything alone. This framework calls for collaboration across public and private sectors, and this process could be slowed if one party from a collaborating group is not yet fully in agreement with all pillars and pathways. Because the outlined strategies address large, systemic issues, they are broad with the potential for challenges and setbacks caused by a variety of confounding factors. Clear indicators will certainly help assess progress made regarding any pillar and systemic oppression, overall.

Next Steps

Despite any limitations, “We the People” has the opportunity to positively influence advocacy and comprehensive policy to eradicate the HIV epidemic. This framework leverages community input to identify key areas where local, state, federal, and private entities can focus monetary and human resources. From this information, robust and culturally-relevant programming and policy recommendations have been derived, and it is recommended that entities enhance and reimagine HIV prevention, treatment, and eradication. Future research could benefit from additional studies addressing the tangible impact of implementing this framework across localities, states, and the nation. To that end, a better understanding of the impact from the WTP implementation could soon be apparent, as BAI is actively designing indicators of progress and developing action steps for specific national, state, and local entities,

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to include federal agencies, HIV-specific organizations, community groups, and those supporting the HIV workforce. From these indicators and entity-specific steps, BAI will be able to provide technical assistance to create reasonable timelines and support the actualization of WTP.

Conclusion

Research consistently demonstrates that addressing systems-level underlying causes is the key to ending HIV (Jeffries & Henny, 2019). “We the People” is a strategy for America, as viewed through an unapologetically Black lens. The Black AIDS Institute works to stimulate investment and engagement across the breadth of government, private entities, and Black America. Thus, BAI uses the WTP framework with its 26 BTAN chapters and affiliates for action at the local and state levels. In addition to outlining action steps to end the HIV epidemic, this article also includes intersectional ways to elevate people already responding to HIV in their communities. This reflects the very core of “We the People.” If Black communities are empowered and resourced, it will be possible to end this epidemic. There is extraordinary potential in Black communities across the nation, which must be free to lead the way toward ultimate victory in our long struggle against HIV/AIDS.

“We the People” is significantly more than a theory; it is the community-informed strategy we can all use to make meaningful progress toward ending the HIV/AIDS epidemic in Black America, and the country, overall. Those within the HIV workforce and those with the desire to make sustainable change must own this fight and break the historically ineffective patterns of our national HIV response, where Black Americans have been left behind at each step. If we hope to finally end this epidemic, Black communities must be positioned at the forefront of the fight with resources and a plan for action. “We the People” provides the blueprint.

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