HIV at an Inflection Point:

Invigorating Community Impact

Elevating Black Leadership and Enhancing HIV Program Accountability Will Sustain Our Critical Successes

HIV changed the world and ushered in a new era of stronger partnerships with local communities in defining, planning and implementing services. It was not simply the virus itself, but the community response that expanded perceptions of what collective action is needed and what it can achieve. Widespread hostility to people with HIV and the communities of which they are a part led to the founding document of the people with HIV advocacy movement, the Denver Principles. Issued in 1983, they just commemorated their 40th anniversary and remain relevant today



The Beginning of the HIV Advocacy Movement: People with HIV on stage at the Fifth Annual National Lesbian and Gay Health Conference releasing the Denver Principles, Denver, Colorado, June 1983.

GIVING A VOICE TO MARGINALIZED GROUPS DEFINES THE HIV RESPONSE

To retain what makes HIV special—community leadership—focused actions are needed:

Center Black People in the HIV Response in the U.S. and Across the African Diaspora

New strategies are needed to bolster and retain Black political, civic, and civil rights leadership on HIV

The Minority AIDS Initiative (MAI) needs to be strengthened

Elevate Community in Planning, Decision-Making, and Accountability

Diverse members of affected communities need to be meaningfully engaged in resource planning and monitoring

There is a need for a greater commitment to improving equity in outcomes across key populations

Broaden Responsibility for Responding to HIV

There is a need to share responsibility for responding to HIV and better support the workforce working on HIV

We need to cultivate cultural influencers to create vibrant entry points to engage in HIV prevention and care

BRIEF 2: This is one of three briefs resulting from consultations with people living with HIV and community, government, corporate, and philanthropic stakeholders held from March through May 2024. Convened to examine progress toward global and domestic prevention and care goals, the dialogues yielded a recurring realization: The HIV response is at an inflection point. Will we keep innovating to develop better prevention and treatment tools and ultimately a cure? Will we keep expanding access to health care and social services? Will we keep removing the scourge of a global crisis? OR: Will we accept persistent disparities, increased polarization, and reduced commitment that results in more HIV and greater challenges? This moment demands that all stakeholders affirm their commitment to the long-term effort to support all people with HIV and the people and places for whom HIV remains a serious threat. We hope that these documents further a critical dialogue.

asserting that "we condemn attempts to label us as 'victims', a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence on the care of others. We are 'People with AIDS.'"

The principles state rights of people with AIDS that includes the right to a full and satisfying sexual and emotional life, quality medical treatment, full explanations of all medical procedures and risks, the right to choose or refuse treatment, to privacy and confidentiality of medical records, and the right to die and live in dignity. This seminal document transformed the doctor-patient relationship by envisioning an active and meaningful partnership. It led to community-led changes in clinical trial designs and treatment strategies, and it led to "people first" language. Action is needed to sustain the legacy of engagement of community leaders and institutions:

2022

IN THE UNITED STATES

Black people make up about 12% of the population, but accounted for 37% of all new transmissions, an 18% decrease compared to 2018.



36%

Black women accounted for 47% of transmissions among women.

Black men accounted for 36% of transmissions among men.

2022

AROUND THE WORLD

Out of 39 million people with HIV and 1.3 million new transmissions around the world, people in sub-Saharan Africa accounted for 66% of all people living with HIV and 51% of new transmissions.



In sub-Saharan Africa, adolescent girls and young women accounted for 77% of new transmissions for young people 15-24.

Sources: U.S. Ctrs. for Disease Control and Prevention, HIV Surveillance Supplemental Report: Estimated HIV Incidence and Prevalence in the United States, 2018–2022 (May 2024), https://stacks.cdc.gov/view/cdc/156513; and UNAIDS, World AIDS Day 2023: Fact Sheet (2023), https://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf.

1. CENTER BLACK PEOPLE IN THE HIV RESPONSE IN THE U.S. AND ACROSS THE AFRICAN DIASPORA

While the popular conception of the beginning of the HIV epidemic focused on white gay men, HIV always has had a disproportionate impact on people of color, especially Black gay men. This was true in the first five cases and one year later, it was reinforced when the Centers for Disease Control and Prevention (CDC) reported by June 1982, "more than 400 AIDS cases had been reported to the CDC; 36% of which were in racial and ethnic minorities."² From the earliest days, Black people have carried a heavy burden of HIV and displayed critical leadership roles in advancing the response that have been underappreciated. Most notably, Dr. Beny Primm, the only African American member and the only one with expertise on intravenous drug use on the Watkins Commission established by President Reagan, played an indelible role on the use of syringe exchange and other harm reduction efforts.³

It is also crucial to remember that two of the most significant turning points in the HIV pandemic came from Black people with HIV. First, NBA basketball player Earvin "Magic" Johnson's announcement that he contracted HIV in 1991 served as a publichealth catalyst for rapidly correcting the public's understanding of who was at risk of infection and remains the single most mobilizing event to U.S. call centers and testing services, resulting in the diagnosis of HIV in 800 heterosexually-identified men.⁴ In the month following his announcement, HIV testing rose by nearly 60 percent in New York City.⁵ Similarly, a year later in 1992, Prudence Mabele became one of the first women living with HIV in South Africa to disclose her status.⁶ Ms. Mabele said she was tired of the silence and stigma surrounding HIV. She was also a founding member of the Treatment Action Campaign which led the effort to secure antiretrovirals despite the AIDS denialism of President Thabo Mbeki.

POLICY ACTION:

New strategies are needed to bolster and retain Black political, civic, and civil rights leadership on HIV.

While HIV remains a critical threat in the lives of Black people, it exists alongside fundamental issues of economic wellbeing, housing, employment, and civil and human rights and the demand for justice that involves tackling crime, policing, voting rights, and the criminalization of blackness. Yet, HIV and related conditions remain a leading cause of premature death for Black people, especially women and Black gay men 25-45 years of age in the U.S. Globally, people in sub-Saharan Africa account for two in three people

with HIV around the world.⁷ This demands that Black communities must be engaged in shaping and fully participating in all efforts to respond to the HIV crisis.

Civil rights and civic organizations still play an essential role in advancing the issues of Black people in the U.S. and around the world. Whether it is the NAACP, the National Urban League or the National Action Network, as well as the National Medical and Black Nurses Associations, and the Historically Black Colleges and Universities (HBCUs), in addition to the Divine 9 fraternities and sororities, and philanthropic organizations, we need these institutions to do more to elevate HIV issues along with the re-emergence of syphilis as a priority political and policy issue for their communities.

Faith communities have played and must continue to play a unique and special role in responding to HIV in Black communities. In dealing with the morally laced issues of sexuality and drug use, leadership from faith communities is especially needed for their ability to reduce stigma and shame, mobilize resources, and to deliver education and services to large numbers of people. In the U.S., clergy leadership of the National Black Leadership Commission on AIDS⁸ was essential in advocating for the development of the Minority AIDS Initiative (MAI) and other crucial resources and that same leadership was at the forefront of the Choose Healthy Life Initiative that mobilized hundreds of thousands to get vaccinated when other systems failed during the COVID-19 emergency.9 In sub-Saharan Africa and the Caribbean, without the infrastructure provided by faith-led hospital and healthcare systems, the response throughout those settings would be hard to imagine.

POLICY ACTION:

The Minority AIDS Initiative (MAI) needs to be strengthened.

In response to the highly disproportionate impact of HIV in Black and Latino communities, the MAI was enacted by Congress and signed into law by President Clinton in 1998.10 Longstanding unease and disagreement about the appropriateness of using race and ethnicity in providing governmental services, however, has impeded the development and utility of the MAI throughout its life. In a Supreme Court decision from before the MAI was established, Adarand Constructors v. Pena in 1995, the Court said all racial classifications must pass strict scrutiny. This means they must (1) serve a compelling government interest, and (2) be narrowly tailored to serve that interest. It also said that race alone is not a sufficient condition for a presumption of disadvantage or the awarding of favored treatment. Federal agency leaders across successive Administrations have moved away from explicitly funding minority-led communitybased organizations (CBOs). More recently, in 2023, the Supreme Court narrowed the ability to use race and to take affirmative action in the context of college admission in Students for Fair Admissions, Inc. v. President and Fellows of Harvard College. Notwithstanding this decision, the MAI remains consistent with Supreme Court precedents and should be an essential tool for reducing HIV transmission and improving HIV health outcomes. Nonetheless, while the program has been maintained for the past 25 years, funding has remained relatively stagnant, and policymakers have rarely highlighted the MAI's essential role, evaluated its progress, or proposed changes to improve it even as the share of new diagnoses among African Americans and people of color broadly has grown since the MAI was established.11

2. ELEVATE COMMUNITY IN PLANNING, DECISION-MAKING, AND ACCOUNTABILITY

Since the beginning of the HIV crisis continuing through more recent experience responding to the

The Congressional Black Caucus has played a critical role in maintaining HIV as a priority.

Amidst overlapping and competing priorities, HIV advocates and allies must do more at the federal and state levels to support current legislative leaders and cultivate new ones. In the current Congress, for example, there are many dynamic Black leaders gaining prominence for their approach to tackling issues. We need more of them not to simply support HIV issues, but to take the time to gain deep knowledge about the complex issues of HIV and related conditions in Black communities and truly become our champions.

Ebola outbreak in West Africa, responding to COVID-19 throughout the world, and in responding to the 2022 mpox outbreak, engaging and enabling trusted indigenous community leaders and organizations has been shown to be a critical element in ensuring that government programs and services are effective and that they reached the most marginalized populations.

POLICY ACTION:

Diverse members of affected communities need to be meaningfully engaged in resource planning and monitoring.

One of the most important innovations stemming from HIV activism is the role of people with HIV and community representatives in meaningful engagement in the policy process. In the U.S. this has come from local planning processes supported by CDC HIV

prevention funding and through HRSA's Ryan White HIV/AIDS Program (RWHAP) planning councils and consortia. While no planning process has been perfect, these bodies often require representation of at least one-third of members being people with HIV unaffiliated with subgrantee recipient organizations, as well as epidemiologists, providers, and others. Federal funds are awarded to the chief elected official in a jurisdiction and they must administer grant funds consistent with the priorities established by the planning bodies. This has been a critical mechanism that seeks to ensure that services are directed to address the greatest unmet needs and that the most marginalized groups have their needs met. In many jurisdictions, however, the public health agency can become adept at paying lip service to established community priorities and funding services or populations with more political clout. Through the President's Emergency Plan for AIDS Relief (PEPFAR) program, there is a somewhat analogous process for

WOMEN LEADERS HAVE BROADENED THE HIV RESPONSE

Women and children always have comprised a relatively small percentage of the U.S. epidemic and many women advocates often have felt that they need to fight for their place at the table. Yet, women have been at the vanguard of the HIV response from its earliest days as lesbians provided leadership in the establishment of community-based services to care for sick and dying gay men all across the country. At a time when those with AIDS were shunned and our heads of state were largely silent, great women such as Dionne Warwick, Elizabeth Taylor, and **Princess Diana** used their celebrity, talent, and power to engage the public to transform attitudes while embracing people with AIDS. Jeanne White Ginder put the face of a loving mother into the narrative as she advocated and cared for her son Ryan and his continuing legacy for whom the Ryan White HIV/AIDS Program is named.

Just as **Prudence Mabele** challenged the stigma of HIV in South Africa, several women changed the perception of HIV in the U.S. **Belinda Mason** who became the first person with HIV appointed to the National Commission on AIDS in July 1989 by U.S. President George H.W. Bush and also was the first know person with HIV to testify before Congress when she spoke in support of the Americans with Disabilities Act which became law in July 1990. **Elizabeth Glaser**,

who spoke on her experience with AIDS at the 1992 Democratic National Convention, where she criticized the federal government's under-funding of AIDS research and its lack of initiative in tackling the AIDS crisis. Mary Fisher, whose "A Whisper of AIDS" speech at the Republican National Convention in 1992 in Houston shifted the conversation also spoke again at the Republican National Convention in 1996 in San Diego. Belynda Dunn was tireless in mobilizing the faith community response and as an advocate to push insurance companies and Medicaid to change their policies so that people with HIV could receive organ transplants.

Today, their work continues with the leadership of many women including Dawn Averitt, a woman with HIV who was often a solitary female presence in early HIV treatment advocacy and who founded the Well Project in 2002. **Dázon Dixon Diallo** founded SisterLove in 1989 as an HIV services and reproductive justice advocacy organization in Atlanta that continues to provide not only HIV services, but act as a strong voice for reproductive rights and reproductive justice in the U.S. and South Africa. Cecilia **Chung** is a Founder of San Francisco Transgender Advocacy and Mentorship (SF TEAM). The Positive Women's Network founded in 2008 by 28 diverse women with HIV has played a significant role in addressing a range

of issues from HIV criminalization to reproductive rights and reproductive justice. **Bamby Salcedo** is a longtime transgender activist who founded the Trans Latin@ Coalition in 2009.

Adolescent Girls and Young Women

In 2022, girls and women accounted for 63% of new infections in sub-Saharan Africa with 4,000 adolescent girls and young women acquiring HIV every week (UNAIDS). Despite substantial declines in new HIV infections globally, the HIV epidemic continues to disproportionately impact adolescent girls and young women (AGYW) in many countries. In response to their disproportionate HIV risk, PEPFAR launched the Determined, Resilient, Empowered, AIDS-Free, Mentored and Safe (DREAMS) partnership, on World AIDS Day 2014. Now implemented in 15 countries, DREAMS provides a comprehensive package of core interventions developed in partnership with young women and girls to address key factors that make them particularly vulnerable to HIV. These include lack of access to comprehensive reproductive health knowledge, family dynamics and structural barriers (i.e., gender-based violence, exclusion from economic opportunities, and a lack of access to secondary school).

developing country operational plans (COPs) that involve stakeholder engagement and are intended to ensure that U.S. resources are directed to epidemiologically sound purposes and to ensure that key populations (i.e. LGBTQ people, people who engage in sex work, people who use drugs) receive an appropriate level of services.

Without access to culturally appropriate, high-quality services, the world will not end HIV by 2030 or epidemics of other infectious diseases including COVID-19, TB, malaria, viral hepatitis, sexually transmitted infections (STIs), nor prevent overdose and other harms related to drug use.¹² Indeed, the U.S. is a signatory to the 2021 *United* Nations Political Declaration on HIV/AIDS that set 2025 targets to have 30% of testing and treatment services, 80% of prevention services to high-risk populations, and 60% of social-enabling services to be delivered by community-led organizations.¹³ Assuring accountability at the local, county, and state/provincial levels must ensure that there is transparent priority setting and funding processes that allocate adequate resources to the most impacted populations. Especially in places in the U.S. and around the world with a poor history of respect for human rights or fiscal governance, the U.S. must invest more strongly in local, regional and global civil society networks to ensure access to services, identify issues that require improvement, and communicate and advocate for best practices. Strengthening community-led monitoring (CLM) by people with HIV caucuses and other organizations comprised of community representatives is strongly urged to protect limited resources from waste and mismanagement, as highlighted by the 2023 UNAIDS report, Let Communities Lead.14

While recent changes to the COP process and the push for country-ownership are essential for sustainability, we must guard against the potential to diminish the role of civil society resulting in worse outcomes for key populations and a reversal of gains. Both in the U.S. and in the PEPFAR program, we already have witnessed an erosion of the role of civil society and governmental entities often are not sufficiently responsive to community demands. There is a need to institutionalize and mandate CLM in all HIV programs to improve accountability and impact.

POLICY ACTION:

There is a need for a greater commitment to improving equity in outcomes across key populations.

Even as we make progress at improving outcomes in all groups, outcomes for the most advantaged populations seem to always improve more rapidly expanding disparities. Nonetheless, intentional efforts to overcome inequities can produce results and what we measure matters. In recent years, both through PEPFAR and U.S. domestic efforts, setting goals and measuring progress toward specific targets has driven progress. Therefore, our efforts to improve core clinical outcomes are not sufficient if they are only reported at the national or local levels aggregated for all people. Programs must elevate a commitment and accountability for improving outcomes by disaggregating data and setting specific outcome goals for key populations and racial and ethnic minority groups.

While there are large disparities across many HIV metrics, within the Ryan White HIV/AIDS Program, disparities in viral suppression have been greatly reduced. In 2022, 89.6% of all clients were virally

DEVIANT SHOWS HOW TO EMBRACE SEXUAL HEALTH AND HIV SERVICES IN A BROADER MISSION FOR BLACK AND BROWN LGBTQ PEOPLE

Deviant (https://www.deviant.live) is a relatively new and innovative organization that promotes popular social gatherings for queer people of color that serve as hubs for both behavioral interventions and to provide a connection to health resources. These events provide just one model for how cultural influencers can support HIV prevention and care. Such individuals and organizations can help to produce the next generation of HIV community champions.

Founded in 2019 by Micah Marquez (Founder/CEO) and now operating alongside Montell Stansberry (COO), Deviant hosts unconventional, yet fun and informative parties, panels and game nights across the U.S. for all queer people, but their primary audience is Black and Brown gay men. They assert that Deviant is a "movement toward a free, inclusive world for all queer people of color," where they create safe and supportive spaces for Black and Brown queer people to explore their sexual and social identities while unpacking the prison of shame. Their operations embrace the ideals of sex positivity, body positivity, and harm reduction. They want everyone regardless of skin color and body type to feel psychologically liberated, seen, and celebrated. Empowering these minority communities with positive messaging around self-esteem and pleasure is their first step in reassociating sexual health and overall healthful decision-making.

Deviant's work is critical not only for the way it gives its community the language to talk about and consider sexual health, they also partner with local organizations and health departments to provide sexual health services at their events. This includes HIV testing, PrEP, and post-exposure prophylaxis (PEP), as well as STI screening information and Doxy PEP, i.e. doxycycline that is dispensed for use as post-exposure prophylaxis to prevent acquisition of bacterial sexually transmitted infections (STIs) for gay and bisexual men and transgender women. Another initiative is their "Cocktails and Conversations" series that creates an entertaining and engaging safe space for curated conversation with community members on sexual health and other healthy living topics.

The health care workforce in the U.S. and globally is over-extended and weak in many places. Given the huge role of the HIV workforce in responding to COVID-19, mpox, and other syndemic diseases (STIs, viral hepatitis, and the opioid crisis), it is often burned out and dealing with unaddressed trauma.

suppressed, including 87.1% of Black clients and 91.3% of Latino/a clients.15 Globally, many countries experience generalized epidemics concentrated among heterosexuals, but key populations including gay and bisexual men and transgender women, people who engage in sex work, people who drugs, and people who are incarcerated, are highly disproportionately affected, yet face enormous state-sponsored and community-led hostility and violence. While there are no magic bullets to overcome these obstacles, policies can ameliorate and reduce their impact. In recent years, as some countries, including the U.S. have lost ground on human rights others such as Botswana, Gabon, Angola, Bhutan, Antigua and Barbuda, Barbados, Singapore, Saint Kitts and Nevis, the Cook Islands, Mauritius, Dominica, and Namibia all have repealed laws that criminalized LGBTQ+ people, facilitating progress toward their HIV prevention and treatment goals.

3. BROADEN RESPONSIBILITY FOR RESPONDING TO HIV

There was a time when HIV was a hot new topic amplified with visible evidence of its toll by the death of high-profile individuals such as ABC News anchor Max Robinson and the urgency of the crisis generated interest in many people across society to step up and provide support. This included health care and social services professionals and volunteers. Whether it was medical students studying infectious diseases, or increased interest in public health and working at CBOs, public attention to HIV drove interest in working professionally in the fields of infectious diseases and public health. Today, people entering clinical care and public health have no direct experience with the early days of the HIV epidemic and often only a cursory knowledge of the history of HIV activism. Their motivations for dedicating themselves to HIV and related issues may be very different. Of course, nobody wants a return to the days of front-page news centered on death and gloom. Yet, it is urgent that a sense of purpose be built around past successes and future goals that encourages a broadened responsibility for responding to HIV and better supporting the people currently doing the work, especially within the communities and populations that have been impacted the most.

POLICY ACTION:

There is a need to share responsibility for responding to HIV and better support the workforce working on HIV.

The health care workforce in the U.S. and globally is over-extended and weak in many places. Given the huge role of the HIV workforce in responding to COVID-19, mpox, and other syndemic diseases (STIs, viral hepatitis, and the opioid crisis), it is often burned out and dealing with unaddressed trauma. Many of these workers are Black, which underscores our prior recommendations for centering Black people in the HIV response. On top of this, challenges with health care financing and ever-present cost-cutting seems to be piling on more work in clinics and CBOs than is sustainable. This is happening as an initial cohort of health care professionals that got their start in HIV early in the pandemic and have memories of what it was like at the beginning are retiring. We are not recruiting enough people willing to train in infectious disease or willing to make career-long investments in working in HIV services delivery.

One way to strengthen the workforce is to broaden responsibility for HIV services. This includes transforming clinical practice to utilize team-based approaches that spread responsibility off of one provider. As the field seeks to address other syndemic conditions, such as syphilis and other STIs and emerging infectious diseases, as well as social and discriminatory factors that impede ongoing care engagement, this also can create more options for expanding the HIV care team. Additionally, primary care should be tasked with doing more to provide HIV prevention and care. Similar efforts are needed to expand knowledge of the unique challenges and needs of people with HIV by other social services providers. Increasing compensation, loan forgiveness and other financial awards are one aspect of what is needed, but the creation of fellowships and professional and personal development opportunities are important, as well as creating recognition opportunities to express gratitude.

POLICY ACTION:

We need to cultivate cultural influencers and trusted sources to create vibrant entry points to engage in HIV prevention and care.

Not all essential HIV work will be done by full-time HIV workers. There is a need to create new ways to contribute to the cause of responding to HIV. While celebrity culture is often criticized, the goal of mobilization is to encourage large segments of the public to care about an issue and various people with public platforms have the influence to do this essential work.

Starting in the early days of the HIV pandemic, Madonna has been a consistent voice in rallying support for HIV causes and educating the public on sexual health. More recently, Beyoncé has used her artistic talent and clout to lift up the lives of Black queer people in ways that continue to transform the culture. Beyond traditional Hollywood celebrities that may speak of HIV issues at luxury events, the rise of social media has broadened the opportunities for individuals to establish their own platforms and has created new opportunities for more extended and often intimate engagement. This includes individuals with large followings on social media, as well as event promoters that hold large parties and are skilled at exciting people. We must also do more to engage, provide information and resources to, and support trusted sources to reach our goals whether it is the leader of the local faith ministry for the homeless or owner of a gathering place where people use drugs.

As we recognize that preventing and treating HIV is wrapped up in promoting sexual health, these individuals are helping to create a language around sexual health that retains the interest of people and can help individuals to resist internalized stigma whether it is for their sexual orientation, gender identity, or HIV status. Part of the advantage of leveraging such individuals as HIV ambassadors is that they are removed from official governmental communication channels, and they speak a language that diverges from the evidence-based scientific approach often used by public health. This enables such individuals to generate trust that can help to make information about HIV, sexual health, harm reduction, and other issues to be received more effectively.

THE TIME IS NOW

A throughline of the HIV response has been community and community activism. We make demands of government, of society, of the health care system, and of ourselves. This is what keeps so many people healthy and has saved so many lives. Our challenge today is not to fix something that is irretrievabl broken. Rather, it is to preserve something that is precious and strengthen it for now and the future. We can keep improving and sustaining a societal commitment to ending the HIV pandemic by taking steps to maintain the community vibrancy we have nurtured over the past forty plus years.

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DISEASE FOLICE

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