

Black Lives Still Matter

Uplifting social justice and HIV

March 29, 2021 By Olivia G. Ford

“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 “We the People: A Black Plan to End HIV” by the Black AIDS Institute

Amid the terror and confusion of a new pandemic in 2020 that had driven the world to stay inside, police continued to murder Black people. Fatal violence against Black transgender women was its own epidemic.

A federal administration fanned these overlapping fires with its rhetoric, policies and nonresponse. And we had nothing else to do but watch.

Uprisings across the globe were swift in response to the murders of George Floyd, Breonna Taylor, Dominique “Rem’mie” Fells, Tony McDade, Riah Milton and too many others, but they did not come out of nowhere. The slow, steady growth in public support for the Movement for Black Lives surged nearly as much in the two weeks following George Floyd’s killing as it had in the previous two years, according to New York Times polling.

More people were engaging in conversations around shifting resources from police departments and investing them in services positioned to ensure true safety for all community members; in some cities, the idea gained momentum and yielded results. And this time, everyone—from massive corporations to celebrities to nonprofits—was sharing “Black Lives Matter” messaging. HIV organizations were no different in their clamor to signal support for this popular cause.

Corporations want to make money, reminds Maxx Boykin, a seasoned movement organizer and current policy and organizing manager at the Black AIDS Institute, which is committed to centering Black experiences in all facets of the HIV response. “They will say ‘Black Lives Matter’ because it will continue to help them make more money and say that they’re on the right side of history.” He reserved particular critiques for HIV organizations that engage in what could be called performative allyship.

“They’ll put ‘Black Lives Matter’ on everything, do a number of Black Lives Matter events; they’ll put Black folks in their ads and tell them to come to the AIDS Walk,” Boykin says. “But when it comes down to meaningful involvement of people with HIV, the meaningful involvement stops at

meaningful involvement of Black people. All those organizations should do severe work around what it truly means to say 'Black Lives Matter' but not have Black lives actually representing you."

"Government agencies charged with ending the HIV epidemic have received billions of dollars, and organizations charged with providing vitally needed services have received millions of dollars. However, this 40-year effort has failed to reduce the level of HIV in the Black community significantly."

—from the Black South Rising agenda

"It is our responsibility to pressure institutions from the clinic to the government, from funders to the courtroom, to act in the service of racial equity and justice, and to divest from the interests of white supremacy."

—from "A Declaration of Liberation: Building a Racially Just and Strategic Domestic HIV Movement" by the HIV Racial Justice Now coalition

Once upon a time, when she was new to HIV work, Venita Ray espoused the same behavioral and biomedical buzz phrases as her white peers. "'It's 100% preventable' or 'Testing! Know your status!' All of that stuff may still be true," she muses. "But I didn't get that this is systemic."

Ray hadn't made the connection between Blackness and the disproportionate impact of HIV when she was diagnosed in 2003. That happened when she began working with her local HIV planning council. She found herself at tables where no one looked like her.

"We would talk about the data, and it's always predominantly Black. But that's the only part of Black that would come up in the conversation, like the data was neutral," she says.

By 2016, leading the development of an Ending the Epidemic (EtE) plan for her home city of Houston, Ray knew she couldn't be party to the same conversations about testing and treatment, adherence and "the down-low" over and over again.

She was explicit that Houston's EtE planning would employ a social and racial justice approach. "That's when I discovered the total uncomfotability of talking about race," she remembers.

Ray struggled through innumerable conversations with well-meaning, uncomprehending white colleagues about the impact of historic and present-day racist oppression and trauma on Black people's health outcomes. Progressive white people, as antiracist guru and White Fragility author Robin DiAngelo, PhD, has put it, can be particularly hard to talk to about race "because we tend to be so certain that it isn't us," DiAngelo told Teaching Tolerance magazine in 2019. "It doesn't allow for humility, and, to be direct, it's quite arrogant. So we don't tend to be receptive at all."

These frustrating conversations spurred Ray to find others in the HIV community who also considered addressing the effects of racial inequity essential to the HIV response. She became a founding member of the HIV Racial Justice Now (HRJN) coalition in 2017. The group released the statement "A Declaration of Liberation: Building a Racially Just and Strategic Domestic HIV Movement" in November of that year.

The document defined racial justice as "the collective practice of people of color and allies to identify, dismantle and heal from the many external and internal harms of structural and institutional racism." Ray now had an HIV-focused tool to support what she had been saying in rooms for years. [Editor's note: The author of this article is a member of the HRJN Steering Committee and a coauthor of "A Declaration of Liberation."]

Ray introduced "A Declaration of Liberation" to the AIDS United Public Policy Council, an influential U.S. HIV policy group where she represented her employer at the time. Her boss pulled her aside before a meeting and asked her: "'Are you showing up as an activist, an advocate, a woman living with HIV or a policy person?'" Ray says. "I was being asked to choose—I realize now. I was like, 'How about all of them?' But what was the question for?"

Years of persistence by Ray and other advocates in pushing the philanthropy network Funders Concerned About AIDS (FCAA) to engage around racial justice issues recently led FCAA to form a Racial Justice Working Group, which was announced alongside data revealing that a scant 4% of total U.S. HIV philanthropy dollars support Black-focused organizations.

Ray was also among the group of Black HIV advocates in the U.S. South who spearheaded Black

South Rising. Formed last year, the collective of activists has released a political agenda based on thorough feedback from across the region and provides incisive guidance for increasing and supporting Black HIV leadership.

“Organizations, health departments and others have failed to serve our communities and have been allowed to operate without accountability,” reads Black South Rising’s statement announcing its launch. “If you work for us, you must answer to us.”

For Ray, the grounding in unapologetic Blackness by the Movement for Black Lives “has given me the language to be that same way,” she says. “I won’t let it go, and I know others won’t.”

Since 2018, Ray has served as deputy director at Positive Women’s Network-USA, where a root-cause analysis and a justice lens are foundational aspects of the organization’s work. But even at a supportive group whose staff is largely drawn from the people it serves, racial dynamics are complex and can be exhausting.

“Finding space to replenish and nourish ourselves is important,” says Raniyah Copeland, president and CEO of the Black AIDS Institute (BAI). The restrictions and innovations made necessary by COVID-19 led her to digitally summon her nationwide network of Black executive leaders in HIV to see how others were getting through this moment. “Even before this pandemic, for folks who do HIV work, our work every day is literally life and death,” Copeland adds. “That can be a lot.”

Ray is among the director-level leaders who have found respite in the nascent digital network Copeland has created, which is more support group than strategy call. “Part of Black resistance is we get so much joy from being together,” Copeland marvels. Though the group first assembled informally, it fits well with BAI’s value of Black empowerment and its overall mandate to nurture Black leadership.

Another of BAI’s functions has been to hold a Black mirror to the U.S. HIV community and expose its contradictions and biases. Copeland identified several levels at which anti-Blackness surfaces in HIV work, from played-down microaggressions by non-Black staff, which affect the climate for clients, to Black people working at an organization for years and never being promoted to the higher echelons of HIV leadership.

“Most of the big HIV organizations across the country are led by non-Black people, even though Black people living with HIV make up almost half of people living with HIV in the United States,” Copeland says. “How did we get to a place where we have these multimillion-dollar organizations and then you have struggling Black- or brown-led organizations in the same city?”

On National Black HIV/AIDS Awareness Day in 2020, BAI released “We the People: A Black Plan to End HIV.” “We will never end the epidemic without tackling the sources of Black people’s vulnerability to HIV,” the report reads. “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.”

The plan comprises four pillars, each one accompanied by practical and actionable recommendations, which institutions are encouraged to adopt as a framework to guide their work and adapt as needed.

The four pillars are:

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 health care 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.

“Unless you are specifically being antiracist, you are holding up racist systems and institutions,” Copeland concludes, adding that she feels this connection isn’t being made strongly enough. “Maybe that is one of the critical pieces needed to get us to the end of HIV.”

“Systems and organizations exhibiting racism and bias—intended or unintended—must change or be defunded.”

—from the Black South Rising agenda

“It is really important to fund organizations where Black queer and trans people are at the helm and make sure that those organizations are funded and well resourced for them to build power,” says Bré Anne Rivera.

To that end, Rivera founded and directs the Black Trans Fund. An incubated project of the justice-focused Groundswell Fund, the Black Trans Fund launched in January 2020, just before COVID-19 hit the United States. Rivera was surprised to find that funds still rolled in to support communities highly impacted by shutdowns, which enabled her to continue fighting the violence, murder and systemic devaluing faced by Black people and particularly Black trans women.

Bré Anne RiveraMax Woltman

As a result, the Black Trans Fund is on track to award \$500,000 in grants directly to organizations led by Black trans people on the ground. For many of these organizations, says Rivera, it was their first grant. They have even been able to connect with additional funding sources through their engagement with the Black Trans Fund. Under no illusion that this swell of funds will be available forever, she asks, “What are we doing now to make sure all of these organizations, initiatives and safety nets are going to be available in the future?”

For Rivera, the challenges Black trans and queer communities face encompass “all the issues I feel are plaguing Black communities,” she says. “Queer and trans folks have really good experience with naming those issues, the impact and how folks can change them.” She cofounded Trans Sistās of Color Project (TSOCP) in Detroit in 2015 to support and uplift trans women of color in her home city. She is currently based in Albuquerque. “TSOCP is a people of color organization, but Black trans women did the work,” she says. “We did the fundraising, and we received a lot of the backlash.”

Back then, she and her cofounders wanted to do mutual aid. Funders were loath to support such efforts. “There were so many questions [from funders] around ‘Why is it important? How do you know that people are using it for the stuff they say they’re going to use it for?’” she remembers.

The term “mutual aid” (a voluntary reciprocal exchange of resources and services) has become familiar to millions more people in recent months as a result of ad hoc networks assembled, or

repurposed, in response to the myriad desperate community needs created by the lack of a coordinated response to COVID-19.

But for Black trans women, who have always found ways to survive and support one another outside of systems that do not cater to and frequently harm them, the concept is not new. “When I was doing that intentionally for Black trans communities, there was so much pushback,” Rivera says.

“Now it’s just like, ‘Everyone needs it, so it has to happen.’ COVID was a reminder that Black trans people were forward-thinking when it came to what it really means to support folks,” she says.

For instance, Rivera notes, her docket of potential grants does not mention the epidemic level of violence directed at Black trans women in their own communities. What it does describe is meeting numerous key needs, such as housing and food, and these needs being met as a response to violence and a step toward liberation for Black trans communities and, by extension, all Black people.

“I am unapologetically creating something for Black trans folks,” Rivera says of the Black Trans Fund. “I am happy about that. It brings me joy!”

“Tackling multiple levels of stigma [and] criminalization and dismantling systems are possible, but only if Black leaders have the external and internal resources to do this work and find the best platform for their work.”

—from the Black South Rising agenda

POZ first interviewed Ashton Woods in 2016. Since then, as a founding organizer of Black Lives Matter Houston and someone involved with several other groups, he has been doing the work he has always done (“except it’s on steroids,” he says), ensuring that communities have what they need while pushing back on hostile policies. He has twice been a candidate for public office in Houston. He didn’t win, but winning wasn’t necessarily the point.

“The whole idea of running was to educate people,” explains Woods, who ran on a simple criminal justice reform platform. “They can’t just focus on the Trump in the White House but need to focus on the Trumps in the backyard.”

Ashton Woods
Courtesy of Ashton Woods

By being a candidate who listened to people, was knowledgeable about their concerns and openly connected issues in his own life—such as living with HIV—to the challenges faced by voters, Woods reminded people in Houston that elected officials work for them and are accountable to them and that voting ought not to be just about representation for its own sake.

“It doesn’t matter if that person is Black and gay,” Woods says. “You have people who are from marginalized communities who perpetuate hate.”

Another important part of engagement around local races is teaching people who to hold accountable for particular issues and where to go with their concerns. “Things get passed into law or pass through committees because no one is there to say, ‘Hey, there’s a problem with this,’” Woods says. “Now, people are showing up everywhere.”

Supporting leaders to be able to directly challenge individuals and institutions in power is what Toni-Michelle Williams does. In her five years as executive director of Atlanta's Solutions Not Punishment Collaborative (SNaPCo), a project led by Black trans people, she built two leadership programs for Black trans and queer folks who have experienced violence, been incarcerated, engaged in sex work and/or are living with HIV.

"By building the leadership of Black trans and queer folks, we are supporting our right and need and desire of belonging and interconnectedness," Williams says. "We're talking about teamwork, coordination and community—what it means to lead."

SNaPCo operates within an abolitionist framework, which means divesting from law enforcement, investing in wellness and restoration in communities, and envisioning and building toward a society without prisons. The organization also engages in “transformative campaigns that liberate everybody Black in Atlanta”—such as the successful push to close and reimagine the Atlanta City Detention Center—and campaigns that center Black trans and queer leadership.

SNaPCo’s model of investing in leadership development “politicizes us in order to build the capacity for us to challenge cis people, straight people, white people and non-Black people to center us and to take many steps back so that our table has more equity and more voices and representation,” Williams says.

“We have to have the capacity not just to sit at the table and listen and ‘be a part’ of the conversations but to lead those conversations,” Williams explains. “We know that a part of leadership is challenging people and calling people to be their best selves, even when it’s uncomfortable and even when it hurts.”

Editor’s Note: In the print version of this story, the photo credits for Venita Ray and Toni-Michelle Williamson were incorrect.

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<http://beta.docker.realhealthmag.com/article/black-lives-still-matter-hiv>