



## **New paradigms of activism: HIV/AIDS and Black Lives Matter**

*How ACT UP's early victories and missteps exposed the need for an inclusive Black movement*

By Kali Villarosa

By 1987, six years after the identification of a strange illness in gay men uncovered the AIDS epidemic, 15,000 Americans had lost their lives and the earliest medication for treating the virus had just become available.

As thousands mourned lost loved ones and policymakers continued to implement anti-queer provisions into public health budgets, activists breathed life into a radical direct-action group called the AIDS Coalition to Unleash Power. The movement would later become known to the world as ACT UP.

From a ragtag meeting hall in New York's West Village, young queer advocates, collectively organizing, strategized about ways to bring national urgency to the struggles of those navigating the virus, by now identified as HIV. ACT UP's first demonstration, on Wall Street, targeted pharmaceutical companies by protesting the cost and availability of HIV drugs. Other actions shut down New York City's Grand Central Station and chided the U.S. Food and Drug Administration (FDA) about lengthy drug approval processes. Ongoing civil disobedience halted traffic with die-ins and kiss-ins and took over broadcast stations. Those brazen, public acts beckoned discomfort to attract attention and elevated a new civil rights movement.

ACT UP defined their fight to end the epidemic under the following [strategies](#):

- Sustained investment in research for new medicines and treatments for HIV/AIDS and related co-infections
- Equitable access to prevention and care for HIV/AIDS and healthcare, in general
- Adequate attention to the structural drivers of the HIV/AIDS epidemic, such as stigma, discrimination, and poverty

At the time, such goals focused on the needs of gay men, who accounted for the majority of infections. Already facing sexuality-based discrimination, the virus brought new fears of rejection, loss of health care, employment concerns, and legal reprisals.



With little acknowledgment from the government and the scientific community, ACT UP activists took it upon themselves to offset the myriad issues that inhibited adequate responses to HIV/AIDS. They formed [committees](#) to address issues including needle exchange, citizen science, housing justice, treatment, data, testing, and disclosure. Each group functioned autonomously but all were held together by ACT UP's belief that through deep solidarity and individual education, members could derail the pandemic.

And they did. Members used legislation to redirect federal funding as well as alter the practices of insurance companies, healthcare providers, and pharmaceutical firms to bring antiretroviral drugs to the market. More than [23 million people](#) continue to live today because of ACT UP's advocacy.

Still, for all the gaps that were bridged, most ACT UP activists had white faces. That tracked with a drastic decline in HIV/AIDS prevalence among white men—but not as much for others.

### **White privilege and Black erasure**

Those early ACT UP activists failed to recognize their privilege or the consequences of overlooking intersectionality, a term coined by Black feminist and critical race theory scholar [Kimberlé Williams Crenshaw](#) in 1989.

Like most pandemics, those most affected by HIV and AIDS overlapped with the populations facing the most rampant social exclusion and institutional discrimination (later designated [key populations](#)): men who have sex with men, sex workers, transgender people, people who inject drugs, and incarcerated people. In the United States today, Black people are overrepresented in each of the key populations. While about 13% of the U.S. population was Black in 2018, [African Americans accounted for 42% of the nation's HIV diagnoses](#). The rate for Blacks, 47.5 per 100,000, is [eight times that of white Americans \(5.6\) and more than twice that of the Latinx population \(20.9\)](#), according to data from the Centers for Disease Control and Prevention (CDC). Black gay and bisexual men bear the heaviest burden of new diagnoses followed by Latinx gay and bisexual men. Black women have the highest rate of infection among their gender. [In 2018, 57% of U.S. women diagnosed with HIV were Black](#).

Black erasure dates back to [the beginning of the U.S. HIV/AIDS epidemic](#) when the June 5, 1981 edition of the CDC's Morbidity and Mortality Weekly Report described



pneumocystis pneumonia in five homosexual men in Los Angeles. While not explicitly stated, the report focused on five cases found in white men. Left out were the [sixth and seventh documented cases](#), both of whom were black—a heterosexual Haitian man and a gay African American man.

The exclusion of Black cases and a racial breakdown from the original findings set the stage for decades of delayed outreach and omission from HIV/AIDS advocacy for African Americans. Along with stigma, poverty, homelessness, and inadequate health care, Black people continue to be more vulnerable to the virus.

Still, out of this neglect rose a new slate of activists—including Phill Wilson and his 1999 founding of the [Black AIDS Institute](#)—who recognized the power of direct action addressing the needs of Black people. Like ACT UP and the Black AIDS Institute, Black Lives Matter founders Patrisse Cullors, Alicia Garza and Opal Tometi are fighting another epidemic—the multilayered, merciless disregard for the humanity of people of African descent globally. They acted following the 2012 killing of 17-year-old Trayvon Martin in Florida by neighborhood watch volunteer George Zimmerman, who was later acquitted in the unarmed Black teen’s death.

### **Making Black Lives Matter**

[Black Lives Matter](#) (BLM) began in 2013 as a call to action in response to state-sanctioned violence and anti-Black racism. As HIV/AIDS continues to spread throughout the global diaspora, Black Lives Matter—now a movement—has picked up where previous activism left off by connecting people worldwide around a shared desire to act in solidarity for justice on all levels and in all arenas for Black communities.

In the 1980s and 1990s, many ACT UP activists failed to realize that the state-inflicted neglect that white men with HIV encountered was akin to the daily experience for Black people globally.

In less than a decade, BLM has brought the disproportionate impact of HIV—infections, diagnosis, care, and treatment—among Black people in the U.S. and abroad to the forefront in concert with HIV/AIDS activist organizations like the “unapologetically Black” Black AIDS Institute. The movement calls for the engagement, examination, challenging, and rethinking of how centuries of social inequality fueled by racism and



white supremacy the way for poorer outcomes for Black people living with HIV/AIDS. This is intersectionality in action.

This means that a fight against police brutality is a fight against HIV/AIDS. Calls for access to adequate education and universal health care are recognitions of the disparities in HIV/AIDS prevention. Protests against houselessness and incarceration overlap with HIV/AIDS inequities.

Freedom, equity, and justice for Black people can bring an end to HIV/AIDS.

In 2020, that was the message that could have been advanced more strongly at the AIDS 2020: Virtual, the 23rd [International AIDS Conference](#). Regrettably, this was another missed opportunity. We will not reach the end of HIV until individuals take a deeper look at their personal ideologies, become actively anti-racist, then infuse those ideals into organizations that perpetuate systemic injustices to create change.

Social justice frameworks employed by ACT UP and other activists in the last four decades must now embrace anti-racist structures modeled by the Black AIDS Institute and Black Lives Matter to end to HIV/AIDS.