HIV/AIDS, Gay Communities, and the Struggle for Gay Rights

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The HIV/AIDS epidemic, first identified by doctors in the United States in 1981, devastated gay and lesbian communities. However, the AIDS crisis also sparked a revival of queer activism. With many lawmakers and straight Americans unwilling to take action against AIDS during the first decade of the epidemic, gay communities fought the disease from the ground up. By insisting that the lives of people with AIDS had value—that the living were worth fighting and caring for, and the dead worth remembering—these activists challenged the apathy of government officials and the general public. The movement they formed changed the course of both the AIDS epidemic and the struggle for gay rights in the United States.

From the beginning, AIDS was identified with gay men. The New York Times first reported on the disease with the headline “Rare Cancer Seen in 41 Homosexuals” in June of 1981. Although the disease was also diagnosed among intravenous drug users and hemophiliacs, many thought of it primarily as a “gay” disease. Before the Centers for Disease Control named the new disease Acquired Immune Deficiency Syndrome (AIDS), it was commonly referred to as GRID—Gay-Related Immune Deficiency.

Those diagnosed with AIDS during the early years of the epidemic had likely become infected with HIV—the virus that causes AIDS—during the 1970s. Over time HIV destroyed their immune systems, making them susceptible to opportunistic infections—cancers, viruses, and other pathogens that usually affect people with depleted immune systems. Many of these opportunistic infections were painful and stigmatizing, as well as deadly. For example, the “rare cancer” reported by the Times was Kaposi’s sarcoma, a skin cancer that had previously been seen
mostly in older men. In gay men with AIDS, many of whom were young and otherwise healthy, the cancer produced dark purple lesions, which would become recognizable as a sign of the disease. When the cancer spread to their internal organs, it turned fatal.

Even as the number of people who had died of AIDS complications grew, President Ronald Reagan did little to address the issue. Reagan repeatedly failed to fund AIDS programs during his first term, while conservative advisers urged a response that emphasized abstinence and heterosexual marriage, effectively ignoring gay men. During the first decade of the epidemic, some politicians even suggested the forced quarantine of people with AIDS, and polls suggested that the American public supported the idea. Reagan himself remained publicly silent on the issue, and did not deliver a major speech on the disease until 1987. By the end of that year, over 40,000 people had died of AIDS in the United States alone.

In the absence of a coordinated federal response to AIDS, gay and lesbian communities disseminated information about prevention and provided support to the sick. They operated AIDS hotlines, printed safer sex brochures, and distributed condoms in places where gay men congregated. In some cities, these efforts took the form of new groups, such as the San Francisco AIDS Foundation and Gay Men’s Health Crisis (now GMHC) in New York City. Elsewhere, local AIDS education efforts grew out of existing gay and lesbian health groups, such as Philadelphia Community Health Alternatives and the Fenway Community Health Center in Boston.

As gay men educated one another about AIDS, they sometimes clashed over what the disease would mean for their sexual freedom. In the years since the 1969 Stonewall uprising, urban gay communities had developed open sexual cultures, which offered numerous opportunities for sexual pleasure. During the first years of the epidemic, doctors had not yet
discovered HIV, but many believed that AIDS was linked to sexual contact. They recommended limiting sexual activity in order to prevent the new disease. However, many gay men had come to understand promiscuity as an integral part of both sexual liberation and their very identities as gay men. Having grown up in a world that labeled them as sick and sinful, they saw calls to rein in their sex lives as still more hysterical moralizing.

On the other hand, some tried to reconcile gay liberation to the reality of a deadly new disease. In 1983, the New York writers Michael Callen and Richard Berkowitz published *How to Have Sex in an Epidemic*, a forty-page guide to safer sex for gay men. They did not instruct their readers to stop having sex altogether, but rather gave them instructions on how to engage in a wide range of sexual activities more safely. Callen and Berkowitz emphasized that gay men should think of safer sex not just as a means of self-protection, but as part of their obligation to their sexual partners and to the gay community as a whole.

In addition to education, AIDS groups delivered services to people living with the disease. Many established “buddy” programs, through which volunteers visited people with AIDS to provide both help with daily chores and emotional comfort to people who often felt lonely and isolated. Some organizations also operated housing facilities for people with AIDS. Still others held support groups for people with AIDS, for their loved ones, and for the “worried well”—gay men who were HIV negative but nonetheless anxious, as they watched other gay men around them grow ill and die.

Beginning in the early years of the epidemic, gay men with AIDS also asserted the right to determine how they would be treated, both by medical providers and by American society at large. At a 1983 gay and lesbian health conference in Denver, AIDS activists, including Callen, Berkowitz, and Bobbi Campbell, a gay nurse from San Francisco, drafted the Denver Principles,
a statement of their rights in the context of the epidemic. They rejected the labels of “victim” and “patient,” which they saw as stigmatizing, in favor of “people with AIDS.” Much like feminist health activists of the 1970s, they also demanded the right to be seen by their doctors as complete human beings, with emotional and sexual as well biological needs, and to have a voice in decisions about their medical treatment. By thus framing gay men’s health as a political problem, the Denver Principles set the tone for the future of AIDS activism.

By the middle of the 1980s, it became clear people of color, particularly black and Latino gay and bisexual men, were being diagnosed with AIDS at much higher rates than their white counterparts. However, many local AIDS groups had arisen from the social networks of white gay men, and had mostly white staff and volunteers. These organizations were ill-prepared to serve the health needs of gay and bisexual men of color, whose lives were often shaped as much by racism and poverty as by homophobia. Moreover, many of the bars, bookstores, and bathhouses where early AIDS groups conducted safer sex education existed in unofficially segregated gay neighborhoods, where gay and bisexual men of color often felt unwelcome. Thus, black, Latino, and Asian AIDS activists founded new organizations to address the growing epidemic among people of color. These included local groups, such as the Minority AIDS Project in Los Angeles, and Blacks Educating Blacks About Sexual Health Issues (BEBASHI) in Philadelphia, as well as national ones, such as the National Minority AIDS Council.

AIDS politics entered a new phase in 1987 with the founding of the AIDS Coalition to Unleash Power (ACT UP). The first chapter of the group formed in New York in March 1987. Within a few years ACT UP chapters existed in over a hundred cities across the country and around the world, from Anchorage, Alaska, to Shreveport, Louisiana. The group used direct action tactics, including demonstrations, sit-ins, and political funerals, in which members
publicly displayed the remains of fallen friends and loved ones to make visible the human cost of the epidemic. They were particularly successful at putting “drugs into bodies,” or making new treatments available to large numbers of people with AIDS. ACT UP frequently protested pharmaceutical companies, whom they accused of profiteering from the epidemic. Likewise, ACT UP targeted federal agencies that played a role in AIDS treatment research, including the Food and Drug Administration (FDA) and the National Institutes of Health (NIH). They challenged the agencies to move more quickly in testing drugs to treat HIV and AIDS and to make experimental drugs more widely available to people who were already sick. In this way, ACT UP built on the Denver Principles by claiming a more active role for patients in medical research, as they pushed for the development of more effective HIV drugs.

ACT UP also fought homophobia, sexism, and racism, all of which they saw as contributing to the AIDS epidemic. They staged “kiss-ins,” claiming the right for queer affection to exist in public space. They demanded that the Centers for Disease Control change the clinical definition of AIDS to include the opportunistic infections commonly seen in women, so that women with AIDS would be eligible for the same disability benefits as gay men with the disease. And when the United States government detained HIV-positive Haitian refugees in Guantanamo Bay, ACT UP charged that the poor treatment was the result of racial bias, and staged protests to demand the refugees’ release.

In the early 1990s, however, ACT UP began to unravel. Many members grew weary after years of feverish organizing. Others had been killed by the very disease they joined ACT UP to fight. Underlying tensions among those who remained bubbled to the surface. Some members charged that the goal of “drugs into bodies” put the needs of white, middle-class gay men ahead of efforts to address the epidemic’s roots in homophobia, racism, and poverty. Others believed
that a broad social agenda would dilute the effort to make new medications available to those who were dying. Amid these conflicts, membership in larger chapters declined, while many smaller chapters disbanded altogether. Nonetheless, ACT UP veterans went on to start other key AIDS organizations. These include the Treatment Action Group, a think tank dedicated to improving access to HIV and AIDS drugs around the world, and Housing Works, a non-profit organization that addresses AIDS and homelessness.

The arts also served as an important site of activism in the fight against AIDS, as artists created powerful visual images that drew attention to the disease. In late 1986, the New York artists collective Gran Fury began plastering their “Silence = Death” posters all over Manhattan. The posters featured a pink triangle, which had been used to identify gay men and lesbians in Nazi concentration camps, on a black background, with “SILENCE = DEATH” in white block letters. By connecting AIDS to the Nazi persecution of gay people, Gran Fury likened the American government’s inaction on the disease to genocide. In another sense, the poster’s text served as a call to arms: for gay men, lesbians, and people with AIDS, staying silent and closeted would only lead to more death. The Gran Fury poster would become closely associated with ACT UP, as members sported “SILENCE = DEATH” signs and t-shirts at their demonstrations.

Since 1987, the NAMES Project has collected panels for the AIDS Quilt, a living memorial to those who have died of the disease. Gay activist Cleve Jones got the idea for the quilt in November 1985, during a candlelight march in San Francisco. During the event, participants carried placards with the names of friends who had died of AIDS complications, and at the end of the march they taped the signs to the side of San Francisco’s Federal Building to vent their anger. The patchwork of signs gave Jones the idea for a memorial quilt. He began to solicit quilt squares from those who had lost friends and loved ones to AIDS. By October 1987,
when the AIDS Quilt was displayed for the first time in Washington, DC, it consisted of 1,920 panels and covered an area larger than a football field. Since then, the quilt has grown to over 48,000 panels honoring 94,000 different people, and it weighs over fifty-four tons. In its sheer size, the quilt serves as a powerful metaphor for the enormity of the AIDS epidemic.

Artistic responses to AIDS were also the source of controversy in the “culture wars” of the late 1980s and early 1990s. During this time, conservative politicians and pundits attacked federal funding for controversial works of art. In June 1989, the Corcoran Gallery in Washington, DC, canceled a retrospective of works by the gay photographer Robert Mapplethorpe, who had died of AIDS complications just months before, because the exhibition contained sexually explicit material. Conservative lawmakers objected to the exhibition, which had been partially funded by the National Endowment for the Arts, a federal program. In response, protesters projected two-story-high versions of Mapplethorpe’s works onto the side of the gallery building. Later that year, NEA chairman John Frohnmayer also revoked $10,000 in funding for an art show about AIDS at the Manhattan gallery Artists Space. Frohnmayer claimed that the show had become too political, because the show’s catalog criticized Senator Jesse Helms and Representative Dannmeyer, both of whom blamed gay men for AIDS, as well as Archbishop of New York John Cardinal O’Connor, who opposed the use of condoms for HIV prevention.

Black gay documentary filmmaker Marlon Riggs also became the subject of controversy when his documentary *Tongues Untied* aired on PBS in 1991. *Tongues Untied* explored the experience of black gay men in the United States and the ways in which their lives were shaped by racism, homophobia, and AIDS; Riggs himself had discovered in 1987 that he was HIV positive. Some local PBS affiliates objected to the film’s sexually graphic imagery and refused to
air it. Conservative lawmakers again attacked the NEA for awarding Riggs a grant of $5,000 through the Western Regional Arts Fund. Riggs died of AIDS complications in 1994.

Marlon Riggs was hardly the only black gay artist to explore the impact of AIDS on gay men of color. Black gay writers such as Essex Hemphill, Assotto Saint, and Melvin Dixon used poetry as a means to reflect on the epidemic as part of the history of black suffering in the United States. The black gay writers collective Other Countries published a volume of such work, *Sojourner: Black Gay Voices in the Age of AIDS*, in 1993. Such projects also overlapped with other forms of AIDS activism. Men from black gay AIDS groups such as Gay Men of African Descent (GMAD) and the National Task Force on AIDS Prevention (NTFAP) also participated in Other Countries and contributed to *Brother to Brother*, a collection of black gay men’s writing edited by Hemphill. GMAD and NTFAP also used the arts as an avenue for AIDS prevention among black gay men. They produced short films designed to help black gay men reduce their HIV risk and hosted events to showcase the work of the black gay artists and writers who addressed AIDS in their work.

For gay, queer, and transgender people of color, ballroom culture has also been an important avenue for mobilizing around HIV/AIDS. In cities across the United States, ballroom participants compete at large events called balls to see who can use dance and drag performance to best embody categories such as “Femme Queen” and “Executive Realness.” Many belong to houses, family-like groups that provide members with much-needed support, including advice about safer sex and HIV prevention. Indeed, the ballroom community mainly includes those who are most vulnerable to HIV in the United States—black gay men and transgender women. Thus, some AIDS service organizations stage special “prevention balls” to reach members of the ballroom community with HIV testing and safer sex messages. These include The House of
Latex Ball, organized by GMHC in New York, and the Love is the Message Ball, organized by the Minority AIDS Project in Los Angeles.

Over the last two decades, treatment for HIV has changed significantly. In 1996, AIDS researchers announced a promising new class of treatments—combination therapies. The news came at a welcome time. Other promising drugs had proven ineffective, while the death toll continued to mount. The previous year, 1995, had seen a record number of deaths from the disease, which had become the leading killer of Americans aged twenty-five to forty-four. Combination therapies, however, produced astounding results. People with AIDS who had been near death made remarkable recoveries as their viral loads—the amount of HIV in their bodies—fell to undetectable levels. However, the high price of the new medicines put them out of reach for many people with AIDS, who lacked health insurance or access to public programs to help defray the cost of the drugs. The work of research scientists and treatment advocates had finally paid off, giving people with AIDS a new lease on life—if they could afford it.

However, for many gay men who had lived through the worst years of the epidemic, the “post-AIDS” world was far from simple. Many had nursed friends and partners through AIDS-related illnesses until their deaths, and they had attended countless funerals over the years. HIV-positive gay men who had not expected to live to middle age suddenly found themselves planning for retirement. Some also found a new kind of sexual freedom. Since their undetectable viral loads made them unlikely to pass HIV on to others, they could once again have sex without fear of infecting their partners. However, many still experienced a deep sense of guilt, wondering why they had survived while those they had buried did not.

Recently, HIV treatment has also changed the meaning of safer sex for HIV-negative gay men—and revived old discussions about sexual freedom and responsibility. In 2012, the FDA
approved the daily use of Truvada, a combination therapy, for use by HIV-negative people to prevent new infections. Some criticized early adopters of Truvada as HIV pre-exposure prophylaxis (PrEP), referring to them derisively as “Truvada whores.” These critics argued that gay men on PrEP would be less likely to practice other forms of safer sex. However, doctors encourage the use of PrEP along with condoms, since Truvada is not 100 percent effective at preventing HIV transmission and does not protect against other sexually transmitted infections. But again, the high cost of the medication means that PrEP is far from universally accessible to those who might want to take it.

AIDS both helped and hindered the struggle for gay rights. The disease decimated a generation of gay men who might have contributed meaningfully to the gay rights movement. However, AIDS also mobilized many gay men and lesbians who might otherwise have stayed away from movement politics. The many men and women who came out to friends and family members as a result contributed to the widening acceptance of gay people in American society. AIDS also gave a sense of urgency to the cause of gay marriage by highlighting all of the rights that were denied to unmarried gay couples, as the partners of gay men with AIDS frequently found themselves shut out of decisions about medical treatment, funeral planning, and inheritance by homophobic family members. However, some have criticized contemporary gay rights groups for prioritizing issues such as same-sex marriage over HIV/AIDS even as the disease remains a crisis, particularly among young gay and bisexual men of color.

AIDS left an indelible mark on gay and lesbian communities and the movement for gay and lesbian rights in the United States. Yet the AIDS crisis is not over, and so the rallying cry echoes: Act up. Fight back. Fight AIDS.
Further Reading


