



AIDS Activism

by Geoffrey W. Bateman

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In the United States, glbtq people have played an integral and often leading role in AIDS activism. They were among the first groups affected by the disease, and their collective response has directly impacted the course of the epidemic and greatly influenced AIDS treatment and advocacy.

In 1981, the Centers for Disease Control (CDC) reported that five young gay men in Los Angeles had been diagnosed with pneumocystis carinii pneumonia (PCP). A few weeks later, it reported that another 26 gay men in New York City and San Francisco had been diagnosed with a rare cancer, Kaposi's sarcoma (KS). Although unknown at the time, these rare diseases signaled the beginning of the AIDS epidemic.

By the end of 1981, roughly 200 gay men showed signs of having KS or PCP. The correlation between the sexual orientation of the patients and the disease became so striking that it soon became known as gay-related immune deficiency (GRID).

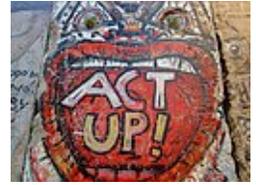
The Role of the Gay Press

Although it quickly became apparent that other groups were also susceptible to this disease, the association between gay culture and AIDS remained strong, prompting heated debates in the gay press. Writers for newspapers such as *Gay Community News* in Boston and the *New York Native* wrote fervently about the causes and implications of the new disease. They were the first voices of a new activism that would consume the gay community and its resources for much of the next decade.

Although not always based on clear scientific evidence, the conflicting arguments that gay writers presented did much to raise awareness of the disease in the gay community. Protective of the accomplishments of gay liberation, some writers, such as Michael Bronski, lamented the demonizing of gay male sexual culture. Skeptical that the urban gay lifestyle, which its detractors characterized in terms of recreational drug usage, multiple sex partners, and sexually transmitted diseases, was responsible for the destruction of gay men's immune systems, Bronski pushed for a more precise scientific explanation.

Other writers for the gay press, such as Michael Callen and Richard Berkowitz, less convinced that a virus caused AIDS, viewed the sexual and social excesses of the 1970s as responsible for the disease. In an article for the *New York Native*, they declared war on promiscuity and cautioned gay men to take responsibility for their sexual lives.

Although confusing and contradictory, the initial lack of consensus among gay writers and activists on the cause of AIDS prompted many to challenge each other, community leaders, and the medical establishment. The chaos forced gay men and their communities to press for more information and take responsibility for educating themselves. According to Stephen Epstein, "[T]he watchword was self-reliance." Gay men had to become their own experts: "ultimately, that was the only reasonable hope gay people might have of surviving."



Graffiti on a remaining section of the Berlin Wall. Photograph by Wikimedia Commons contributor Queerbubbles in 2008. Photograph appears under the Creative Commons Attribution-Share Alike 3.0 Unported license.

Gay Community Response

As many chroniclers of the early AIDS epidemic have noted, in contrast to the other groups initially impacted by the epidemic--Haitians, hemophiliacs, IV drug users--the gay community responded most visibly and most quickly to the new disease. This organized response was due in large part to the legacy of gay liberation, for the social and political institutions that gay men and lesbians had created in the previous decade allowed them to mobilize quickly in the face of this new threat.

The threat was social as well as medical. At a time when the cause of AIDS and its method of transmission remained uncertain, people suffering from the disease were subject to cruel mistreatment and discrimination. Even healthy members of at-risk groups experienced discrimination and stigmatization.

Moreover, the association of the disease with homosexuality helped fuel anti-gay sentiment. Several public officials called for coercive public health policies, including mandatory HIV testing and quarantines. In the eyes of the general public, gay men were seen less as victims of a new disease than as vectors of an infection that endangered the general population. Gay men and drug users were often contrasted with the "innocent" victims of the disease, hemophiliacs and others infected through blood transfusions and children infected by their mothers.

The medical and the social were interrelated, for in the opinion of many observers, one reason the epidemic spread so quickly and penetrated so deeply into the gay community was the hostility and indifference of the government and the larger society to the lives of homosexuals and drug users. Hence the response to AIDS had to be multifaceted: medical, social, and political.

In 1982, gay male and lesbian activists formed the first two AIDS service organizations (ASOs): the Gay Men's Health Crisis in New York City and the Kaposi's Sarcoma Research and Education Foundation in San Francisco, which two years later became the San Francisco AIDS Foundation.

These two organizations worked hard in the early years of the epidemic to provide much needed medical and social support to people living with the disease. They helped educate gay men at risk for contracting the virus, and they organized politically, advocating for the rights of people with AIDS.

Safer Sex Practices

AIDS activists and the early leaders of these organization also pioneered safer sex practices. As it became increasingly clear that HIV caused AIDS, gay men began creating guidelines for preventing the transmission of the virus through sexual contact.

These guidelines began to emerge as early as 1983. In a forty-page booklet called "How to Have Sex in an Epidemic," Michael Callen and Richard Berkowitz created an almost exhaustive list of practices that set the standard for safer sex in gay male culture.

In their early activism on behalf of safer sex, gay men insisted on making it erotic, both to encourage its practice and to celebrate male-male sexuality. Practicing safer sex allowed gay men to continue to participate in gay male sexual culture and still protect themselves from infection. By promoting safer sex, they challenged the demonizing of gay sex that had accompanied the initial discovery of the disease.

Assimilation of AIDS Service Organizations

In the mid-1980s, as Cindy Patton has noted, a major shift occurred in AIDS activism and the ASOs that had been created to respond to the epidemic. Most notable was the change of focus at the Gay Men's Health Crisis (GMHC), which according to critics lost sight of its original mission.

Patton observes that "The shift was *away* from gay liberation-inspired resistance to a hostile government and indifferent medical empire, and *toward* an assimilation of activists into a new AIDS service industry, with its own set of commitments and its own structuring logic."

The assimilation of AIDS service organizations helped transform AIDS into a more mainstream disease, and it certainly helped make possible a governmental response to the disease.

ACT UP and Radical Activism

The institutionalization of ASOs led to a growing division between their supporters and other AIDS activists, prompting a resurgence of radical activism in New York City and elsewhere. In 1987, activists formed ACT UP, or the AIDS Coalition to Unleash Power, and ignited a new phase of AIDS activism when it staged a Wall Street protest against the Federal Drug Administration and the pharmaceutical giant Burroughs Wellcome, developer of AZT, the first drug that proved efficacious in fighting AIDS.

Frustrated by what they saw as the political complacency of GMHC, ACT UP activists began to organize protests and demonstrations, using bold tactics and flashy images to pressure governmental officials and community leaders to respond more thoroughly to the disease. ACT UP demanded more effective and accessible treatment options, challenged the public's bigotry surrounding AIDS, and promoted safer sex and other prevention messages to stop the spread of HIV.

Two of the most striking accomplishments of ACT UP were in improving treatment for people with AIDS and in generating visibility for AIDS issues. Much of ACT UP's initial activism focused on protesting the FDA and drug companies that controlled access to early AIDS drugs and working with them to streamline clinical trials. One of its most striking and visible images was its striking graphic, a pink triangle with the slogan SILENCE = DEATH in black.

Artistic and Cultural Activism

Activism in response to the AIDS crisis was expressed in artistic and cultural terms, as well as in more traditional political forms. A distinguished body of literature, art, dance, poetry, music, film, and performance art kept the disease in the public eye and gave expression to the gay community's sense of rage, pain, and loss.

Prominent writers such as Paul Monette, Andrew Holleran, Edmund White, Armistead Maupin, Terrence McNally, Larry Kramer, Randy Shilts, and Tony Kushner put AIDS at the very center of their varied work. Visual artists such as Keith Haring, Robert Mapplethorpe, and David Wojnarowicz devoted their skill to recording responses to the epidemic. Dancers and choreographers such as Bill T. Jones and Arnie Zane and composers such as John Corigliano used their talent to heighten awareness of the disease, as did a host of performance artists.

Two important collective projects that promoted AIDS activism were the Red Ribbon Project, which established the red ribbon as the international symbol of commitment to people with AIDS and to the AIDS struggle, and the Names Project's AIDS Memorial Quilt, which was conceived as a means of commemorating the lives of those who succumbed to the disease. Not coincidentally, the Quilt's national debut was at the 1987 March on Washington for Lesbian and Gay Rights.

Lesbian Activism

Since the beginning of the AIDS epidemic, lesbians have been active in fighting the disease. They often supported gay male friends as they struggled with the disease, participated actively in ACT UP and other AIDS organizations, and comprised a small number of those infected.

In spite of their involvement, lesbians were often thought to be at little risk for HIV infection. Yet lesbian AIDS activists repeatedly challenged such assumptions, arguing that lesbians participate in many risky behaviors. Women from ACT UP maintained that labeling lesbians as a low-risk group could lull them into a false complacency and put them at greater risk for infection.

Lesbians also often brought a feminist perspective to AIDS activism, prompting many gay activists to consider the disease in the context of a broader movement for social change. Feminists within the AIDS movement have pushed for broader solutions to the crisis, demanding nationalized health care and universal sex education.

Decline of AIDS Activism

Although the disease continues to wreak havoc in the gay community, AIDS activism has waned since the early 1990s, at least in part because of the development of effective treatments for the disease and the lessening of the stigma associated with it. As AIDS has become a mainstream disease, activism has come to seem less urgent than it did in the 1980s and 1990s, at least for those with access to the new medications.

As people with AIDS live longer and the disease has come to seem chronic rather than acute, AIDS activism has become a long term and less explosive struggle. With many of their leaders dead from the disease or now absorbed into the AIDS service industry, ACT UP and other radical groups have grown moribund.

Notwithstanding the monumental advances in drug therapies in the mid-1990s, however, there is as yet no cure or vaccine for the disease.

Legacies of AIDS Activism

One of the legacies of AIDS activism is that it empowered people who suffer from a disease or oppression to take charge of their political lives and establish a greater degree of authority over what happens to them. As Steven Epstein writes, the AIDS activist movement "is indeed the first social movement in the United States to accomplish the large-scale conversion of disease 'victims' into activist-experts."

Yet not everyone believes that AIDS activism has succeeded in making the voices of HIV-positive people central in the debate. Michael Hallett maintains that AIDS activists continue to be marginalized in the struggle to determine the meaning of AIDS in our culture and its place in our social institutions.

He argues that much of what passes for AIDS advocacy fails to serve HIV-positive people, but rather caters to the interests of the AIDS industry, including government officials, non-profit employees, and scholars. He rejects the "assertion that activism has been a highly effective remedy to HIV-positive voicelessness," and "in the battle for control over the social construction of HIV-disease, AIDS activists *have well been ignored and continue to be marginalized.*"

Given the complexity of the AIDS epidemic, there is truth in both assessments. AIDS activists may not have gained control over the disease and its meanings, but they certainly have transformed its political context. Certainly not all issues facing PWAs have been resolved, nor is every PWA able to become an activist-expert.

For those already on the margins because of their gender, sexual orientation, race, class, or age, there are still barriers to treatment and education. Yet the past twenty years of AIDS activism has overwhelmingly improved the lives of PWAs and others. AIDS activists have sped the development of effective treatments for the disease and have helped create acceptance and compassion for those suffering from the disease.

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