
Who Gets a Say? Women and the AIDS Crisis

Emma Brick-Hezeau
Tulane University, New Orleans, Louisiana, USA



Abstract: The early 1990s saw the mobilization of women with HIV, healthcare providers, and large activist groups around the CDC definition of AIDS. This mobilization focused on the exclusion of women's symptoms and illnesses in the diagnostic definition. The implications of this restrictive definition were most visible in low-income communities, among women, and people of color due to lack of access to healthcare, pre-existing conditions, and relative exclusion from medical research and testing processes. This case studies the women who organized to affect change and the role of specialized activists in advocating for marginalized groups. This case focuses on the activist efforts of Katrina Haslip of ACE, Theresa McGovern of the HIV Law Project, and the ACT UP Women's Caucus. Research for this case draws upon pamphlets from organized activist groups, transcripts of ACT UP interviews, lectures from activists about the events of the early 1990s, as well as legal journals and women's healthcare literature. This case outlines the processes by which women have enacted change in the HIV/AIDS activist movement, while addressing the challenges they face surrounding political and medical bureaucracy, lack of political will, and bogged down activist networks. The paper concludes that the most important component in activism is the inclusion of those most affected by the struggle, which was difficult due to the devastating nature of AIDS. In the face of the AIDS crisis, Katrina Haslip and Terry McGovern had to balance political gains versus the immediate needs of affected communities.

Katrina Haslip and the Fight for a Diagnosis

According to the Center for Disease Control (CDC), Katrina Haslip did not have AIDS. She had been in and out of the hospital for months, eventually taking up residence at the New York Roosevelt Hospital in November of 1992, coughing from another bout of bacterial pneumonia with a CD4 cell count of six (Navarro 1992). CD4 cells are a type of lymphocyte (white blood cell) that coordinates the body's immune response (U.S. Dept. of Health and Human Services 2019). HIV is a virus that weakens the immune system by destroying CD4 cells, and as the infection progresses it can develop into AIDS, a syndrome in which the CD4 cells drop and the immune system cannot easily fight off infection. A normal range for CD4 cells in a non-HIV-infected person is about 500-1,500 cells per cubic millimeter of blood. By the most recent CDC definition, a person is diagnosed with AIDS when their CD4 count drops below 200 cells per cubic millimeter of blood (U.S. Dept. of Health and Human Services 2019). The CD4 cell threshold of 200 was not included in the AIDS definition until 1993, disqualifying many (primarily female) patients like Haslip from research, disability support, and AIDS-inclusive resources such as housing. Instead, the definition of AIDS at the time only included men's symptoms, since women were often excluded from research and even consideration from medical professionals (McGovern 1994).

Haslip found out she had HIV while serving time in Bedford Hills Correctional Facility after a pickpocketing conviction. During her time in prison, Haslip was appalled at the treatment of incarcerated women with HIV. "Women were dying in their cells and in the hospitals," Haslip recounted, describing the utter isolation of HIV-infected women in prison, shunned by guards and inmates alike (Navarro 1992, n.p.). Her time at Bedford transformed Haslip, a black Muslim woman born to a working-class family in the suburbs of New York City, into a fiery activist navigating big city politics. Upon her release she knew she wanted to take on the stigma and bureaucratic structures that left women like her suffering and undertreated (Navarro 1992).

Haslip was not alone in this struggle. During the late 1980s and early 1990s, the number of women being diagnosed with HIV was steadily rising (Amaro 1995). However, the CDC based the majority of its AIDS research on the symptoms of white, middle-class men with better access to health care, and for whom opportunistic infections¹ related to the virus manifested differently than in women and those from low-income backgrounds (McGovern 1994). Haslip recognized the importance of increasing the visibility of HIV-positive women, coming out as HIV-positive herself and inspiring more women to come forward. She knew that she had to join forces with other AIDS organizations in order to make real change, but she worried about losing the voices of HIV-positive women along the way (McGovern 2008). Her fight was a hard one, as she was up against the biases of a nation and the institutions that kept them in place. Haslip had to find her place or risk getting drowned out in the cacophony. To what extent could she navigate the specialized legal and activist spheres as a formerly incarcerated woman with HIV? How could she and other women in marginalized communities assert their needs through the legal and political processes required to change the definition?

Women Don't Get AIDS, They Just Die From It

Thanks to years of grueling activism from the AIDS Coalition To Unleash Power (ACT UP) New York, hundreds of thousands of people, mostly gay men, were finally receiving treatment for the HIV and AIDS. Despite victories for the visibility of individuals with HIV and AIDS, accelerated drug trials, and government-subsidized programs to provide for the sick, the population of HIV-positive women was rapidly growing and continued to be largely ignored. Major American magazines like *Cosmopolitan* linked HIV and AIDS with so-called 'deviant' behavior through opinion-editorials and news coverage (Erni 1994). Due to the stereotyping of risk for HIV and AIDS, many in the medical field refused to consider that women might also have acquired the deadly syndrome, withholding official diagnosis from women with dangerously low CD4 cell counts (Patton 1994). Without an AIDS diagnosis seriously ill women found themselves excluded from a large array of housing, disability, research, and support programs designed to assist people living with debilitating AIDS-related opportunistic infections. Though many of the women diagnosed with HIV had documented infections and low CD4 cell counts, their official diagnosis read "HIV positive-asymptomatic," which disqualified most women from both an AIDS diagnosis and disability support (McGovern 1994).

By the early 1990s, independent research had demonstrated a clear link between highly progressed HIV infections and chronic gynecological conditions in women such as cervical cancer, recurring yeast infections, and pelvic inflammatory disease (Kates et al. 2013). However, the CDC

¹ According to the U.S. Dept. of Health and Human Services, an opportunistic infection refers to an infection "that occurs more frequently or is more severe in people with weakened immune systems, such as people with HIV or people receiving chemotherapy, than in people with healthy immune systems," (2019, 126).

did not recognize these symptoms in their surveillance definition of AIDS, which medical and disability programs throughout the world used to determine patient eligibility. Because of the CDC's restrictive definition, hundreds of thousands of HIV-positive women were unable to receive assistance when they could not work or provide for themselves. This led to increased numbers of homeless HIV positive-asymptomatic women, as well as largely ineffective treatment of women for chronic infections in community clinics instead of specialized hospital wards for AIDS. Seropositive² women instead had to undergo lengthy and often unyielding legal processes to receive support, and many declined in health or died during the process (McGovern 1994). Additionally, the limited definition of AIDS excluded women from participation in research studies and drug trials, which meant that the developing medications used to treat AIDS at the time were largely untested for treatment of women's symptoms and bodies (Kates et. al 2013).

Joining Forces

Haslip had undiagnosed AIDS, and though her body was weakened, she still fought for change. After her release from prison, she became heavily involved with AIDS education at a New York health clinic. Haslip would go on to found the AIDS Counseling and Education (ACE) program for incarcerated women with AIDS, as well as AIDS Counseling and Education-OUT for recently released women with AIDS to provide them with counseling, support, and to improve conditions for women both in prison and upon their release (Clark and Boudin 1990; New York Times 1992). During her work in New York City, Haslip began working closely with the HIV Law Project spearheaded by lawyer Theresa McGovern (McGovern 2008). The mysterious woman who worked in the law library and advocated for HIV-infected prisoners fascinated McGovern, who heard about her through the stories of women with whom she had assisted in finding support for HIV and transitioning into civilian life (New York Times 1992; McGovern 2008). Since Haslip was HIV-positive herself, her advocacy meant much more to the people with whom she worked. The seropositive community saw Haslip as fearless and inspiring, as she led other positive women to come forward with their stories, combat HIV stigma, and fight for legal change (McGovern 2008).

Theresa McGovern founded the HIV Law Project in order to provide legal advocacy and support services to low-income women, people of color, and LGBT people affected by HIV. Shortly after graduating from law school, McGovern began working in a New York legal clinic, where she encountered a growing number of HIV cases, prompting her to specialize in HIV and AIDS law. McGovern met Haslip through researching local AIDS education organizations like ACE and ACE-Out (McGovern 2008).

Though the two women came from very different backgrounds, they developed a strong bond over their shared passion: helping HIV-positive women improve their quality of life. Though Haslip's voice was weak and raspy, her message was strong. Haslip was dying from a disease the medical community refused to recognize and was unable receive the official AIDS diagnosis that would make her a candidate for clinical drug trials, disability support, and new research (Navarro 1992).

Though receiving access to medical care remained a pressing issue for HIV-positive individuals, the growing population of women with undiagnosed AIDS needed legal support to challenge the CDC's restrictive definition of AIDS. McGovern and Haslip knew the CDC had a

² This term refers to giving a positive result in a test of blood serum, e.g., for the presence of a virus, referring to the presence of HIV (U.S. Department of Health and Human Services 2019).

reputation for evasiveness and would never give out money or settlements to aid the plaintiffs. However, the pair devised a clever strategy, pursuing litigation against the Social Security Administration's (SSA) benefits programs for unfairly discriminating against women by requiring patients to meet the exclusive CDC definition of AIDS to qualify for disability support and housing (McGovern 2008). On October 1st, 1990, McGovern filed the lawsuit, and the three-year *S.P. v Sullivan* case began³. That afternoon McGovern, Haslip, and around 30 other HIV positive women got on a bus paid for by ACT UP to demonstrate in front of the Health and Human Services building in Washington, D.C. (McGovern 2008). This was the first of many coordinated political demonstrations on which the HIV Law Project and ACT UP would collaborate in order to draw attention to the issue of women, AIDS, and the case against the Social Security Administration.

McGovern represented 19 HIV-positive plaintiffs as their legal counsel as the defendant moved to dismiss the case three separate times (McGovern 1994). The plaintiffs argued that the Social Security Administration had been systematically denying HIV-positive patients' rights to support and disability services through its use of the CDC's restrictive surveillance definition of AIDS, excluding women in particular.

Prior to 1993, the CDC provided basic guidelines for the diagnosis of AIDS. Governments, medical professionals, and disability services in the United States and around the world used this so-called "surveillance definition" to keep track of AIDS cases. The original definition included the appearance of Kaposi sarcoma (KS) lesions⁴ primarily seen in men with no other underlying illness. The limited definition presented a problem for low-income individuals with HIV, many of whom had preexisting conditions due to limited access to healthcare (Patton 1994). Additionally, the definition failed to take into account the other types of opportunistic infections present as the virus progressed in women (McGovern 1994).

During the litigation process, McGovern developed close relationships with her HIV-positive clients, both through the HIV law project and in ACT UP. She often stressed the importance of direct involvement of the women affected by the policies she was fighting to change through all steps of the legal process. However, this became difficult as more and more advocacy groups became involved in the process (McGovern 2008). Activists struggled against the blatant political bias of the Bush administration against the HIV-positive and LGBT communities, as well as the "AIDS industry,"⁵ referring to the overwhelming influence of a sprawling and increasingly bureaucratic network of HIV and AIDS organizations (McGovern 2008, n.p.). It seemed the only response activists could get was from sensationalist and disruptive protesting like ACT UP New York's die-ins that brought these issues to the media and the public eye (McGovern 2008).

ACT UP! Fight Back! Fight AIDS!

The AIDS Coalition to Unleash Power (ACT UP) formed in New York City in 1987 in response to homophobic and alienating policies regarding people with AIDS. Most of the original

³ The primary plaintiff in the case was referred to as "S.P.," and was described as an HIV-positive mother denied housing benefits for herself and her child when she could no longer work due to HIV-related chronic illness (McGovern 1994).

⁴ A type of cancer often present in gay men with sexually-transmitted HIV that has progressed into AIDS (U.S. Department of Health and Human Services 2019).

⁵Hammonds further illustrates the complexity of the fight against AIDS as it transformed: "The fight against AIDS changed from the grassroots activism of groups like ACT-UP and Boston's Multicultural Aids Coalition to a full-blown infrastructure—international conferences were held every year; new medical journals appeared devoted solely to AIDS; nurses, clinical social workers, public health experts, medical researchers, and newly-formed community-based organizations all had their own perspective on the epidemic as they vied for increasing amounts of federal funds. A new category of expert was created out of these efforts: the AIDS worker" (2009, 270).

members were gay men and lesbians living with HIV along with their friends and partners. The group was structured non-hierarchically and was composed of a number of caucuses and committees designed to organize nonviolent direct-action protests (Stockdill 1997). The coalition employed controversial, media-ready tactics such as marches, die-ins, storming offices of key political figures, creating eye-catching art, and producing disruptive political theater (Stockdill 1997).

Former ACT UP organizers Marion Banzhaf and Alexis Danzig recounted the pain and anger present at ACT UP meetings, as activists had to balance planning attention-grabbing spectacles and caring for one another as members suffered from HIV and AIDS (Banzhaf and Danzig 2015, n.p.). ACT UP endeavored to have the needs of people with AIDS at heart rather than larger political goals, which made ACT UP an excellent partner for Haslip and McGovern. The organization championed the visibility of people with HIV and AIDS, making accommodations to “include people who weren't well, who might need to be there in a wheelchair, or who might need their meds when they were in jail, or who might be undocumented, thereby putting them at risk for real jail-time or deportation,” (Banzhaf and Danzig 2015, n.p.). ACT UP members came from diverse backgrounds, and many of them were sick. The organization became a support system for those with AIDS, their families, and friends. Their activism continued for the sick and those who were lost along the way.

Professor and AIDS cultural researcher John Nguyet Erni observed, “the dominant media still consistently ignores the enormously positive contributions to the drug development process brought about by the energetic and multipronged actions of the AIDS treatment activists,” (Erni 1994, 58). Though the grassroots organization became a formidable network for People Living with AIDS (PWAs), its controversial demonstrations painted the group as a fringe, radical interest group. Television and newspaper coverage of ACT UP presented images of anarchist rallies that threatened the morality and sensibility of heteronormative Americans, as ACT UP's power became conflated with a “violent gay agenda” (Erni 1994, 96). Conservative commentary linked the growing political presence of ACT UP with a terrorizing, subversive, and homosexual framework. ACT UP's media-focused campaigns acted as a double-edged sword. While its controversial tactics garnered much attention from the press and made headline news, its radical image and tight-knit community tended to alienate the general American population. The direct actions and jarring imagery put forth by ACT UP both appealed to and repulsed the American public, leading some AIDS- and LGBT-related organizations to distance themselves from the group (Erni 1994). However, the organization's controversial tactics simultaneously appealed to younger LGBT-identifying people who identified personally with the pain and threat of the AIDS crisis (Jennings and Anderson 1996).

Women with AIDS Under Attack

Efforts to provide HIV education to women in the 1980s proved largely ineffective due to the social stigma surrounding the acquisition of the virus. As HIV became synonymous with a deviant lifestyle of drugs, homosexuality, and anal sex, heterosexual women and lesbians alike became increasingly distant from perceptions of risk for the virus (Patton 1994). Even though medical professionals had early reports of women with AIDS in the first few years of the epidemic, the scientific and medical communities at large were slow to recognize that women were more than mere vessels for transmission of the virus to men. Furthermore, the CDC did not begin to analyze the gendered component of AIDS until major public controversy and outcry from activists (Patton 1994).

Patton (1994) also noted that women and men received different levels of medical care. Since women generally received less quality health care and were less likely to go to one consistent physician over long periods of time, doctors were unable to connect women's chronic symptoms as indicative of HIV and AIDS (Patton 1994). Prior to the litigation efforts led by Haslip, McGovern, and the HIV Law Project, the CDC did not include unique women's conditions in the surveillance definition. Unlike the sores and cancers present in the better-researched HIV-positive male communities, recurring vaginal infections that presented themselves in HIV-positive women did not raise red flags for most physicians (McGovern 2008; Patton 1994).

By the mid-1980s, HIV in the United States was rapidly spreading outside the gay male community. New research in public health isolated HIV as a human retrovirus, bringing researchers closer to explaining the causes and transmission mechanisms of the virus (Patton 1994). Patton argues that although these breakthroughs provided important insights into HIV transmission, scientists who were aware of the sociopolitical conditions of the epidemic chose to ignore them (1994). The focus instead was on epidemiologic 'risk groups,' which misrepresented who was at risk through broad generalizations and stereotypes. Though proportions of incidence among men and women in Africa remained relatively equal in proportion, the rate of infection from the virus, which had at first presented itself in gay male and IV-drug using groups in the United States, grew rapidly in female populations (Patton 1994).

By 1983, the CDC published a review of the epidemiologic pathways along which HIV was spreading, identifying the so-called 4-H Club for at-risk populations: homosexuals (referring to men), heroin users, hemophiliacs, and Haitians. The CDC also included female sexual partners of bisexual or intravenous drug-using men and their children (Rodriguez and Manlowe 1997). Women remained relatively invisible, although the medical community regarded them occasionally as potential 'vectors' and 'reservoirs' for infection. If recognized as anything beyond *female sexual partners of men*, researchers generally labeled HIV-positive women as a fifth potential H: hookers (Rodriguez and Manlowe 1997).

An important informational booklet released by the ACT UP Women's Caucus in 1990, *Women, AIDS, and Activism* identified a major inhibitor for women-specific research around AIDS as the exclusion of pregnant women and those of childbearing age from clinical trials. From the 1970s until the early 1990s, the FDA maintained a controversial regulation called the Additional Protections Pertaining to Research, Development, and Related Activities Involving Fetuses, Pregnant Women, and Human in Vitro Fertilization, (McGovern and Manlowe 1997, 45). McGovern and Manlowe (1997) argued that the language of the regulation itself shows the demotion of women's safety over fetuses as the primary concern in women's health issues. The FDA's policies showed bias against women's health autonomy by placing emphasis on fetal risk, even to the detriment of the woman's needs. According to this statute, the father of the fetus must provide consent in order for a pregnant woman to participate in medical research, even in cases of HIV (Code of Federal Regulations 1983). McGovern and Manlowe (1997) contend that the fetus is treated as the trial participant instead of the mother. Thus, they argue, the FDA had reinforced the discrimination against women by restricting their access to clinical trials. ACT UP and the Women's Caucus held several direct-action demonstrations at FDA headquarters during 1991 and 1992 to push for a repeal of the Additional Protections Policy. While the policy appeared to have women in mind, it effectively removed women's bodies from the research pool as well as from receiving important medications, thereby limiting their access to potentially life-saving drugs (Code of Federal Regulations 1983; McGovern and Manlowe 1997).

Though the portrayal of AIDS as a syndrome acquired by “deviants” in the media was largely a political tool, its stigma had a huge impact on the direction of research and policy regarding the disease. AIDS is a textbook example of how the stereotyping of a disease can have real consequences for its treatment in the medical field (Erni 1994). It is clear the CDC guidelines were inadequate for diagnosing AIDS in women, which compromised women’s health and public health overall (Banzhaf and Denenberg 1990). Haslip, McGovern, and ACT UP used legal and direct-action channels to fight the stigma around AIDS and bring awareness to the misrepresentation of the disease. The visibility and foregrounding of seropositive women like Haslip in activist legal work was critical in showing bureaucratic institutions like the SSA and the world at large the harsh realities of life for women with HIV and AIDS.

What Do We Do? ACT UP, Fight Back!

The ACT UP Women’s Caucus grew to become a crucial subcommittee of the organization, drawing upon the activist history of its lesbian members, many of whom had worked in political organizing in the past. Many of its members were involved in the women’s health movement, allowing the group to develop innovative strategies from earlier campaigns and actions (Carroll 2015). ACT UP and WHAM!⁶ Member Emily Nahmanson reflected that the Women’s Caucus “was crucially important to the ACT UP community, and to the AIDS activist movement, because they brought an activist history to the group,” (Carroll 2015, 150). Initially, the Women’s Caucus met through casual ‘dyke dinners’ where members explored their own feelings of grief, anger, and belonging within ACT UP. As a result of this introspective community-building, the women of the group soon determined they should create their own committee that would address women-specific issues during the AIDS epidemic. The first action of the Women’s Caucus was a response to a January 1988 *Cosmopolitan* magazine article suggesting that “American women were not at risk for AIDS, and did not need to use condoms, because they did not engage in the ‘brutal sex practices of Africans’” (Carroll 2015, 150).

When the psychologist who wrote the *Cosmopolitan* article refused to retract his piece, the Women’s Caucus organized their first ever demonstration in front of *Cosmopolitan*’s New York office, disrupting traffic and making headline news (Carroll 2015). They also sent hundreds of condoms each day to Helen Gurley Brown, then editor of the magazine, who later published articles on safer sex practices for women. For the first few years of its existence, the Women’s Caucus primarily focused on safe-sex education. Notable actions from the group included the infamous 1988 Shea Stadium demonstration, where ACT UP men and women bought out an entire section of the stadium, taking up highly visible space in order to hold up banners on live TV reading “AIDS Kills Women” and “No Glove / No Love.” This action was a major victory for educational exposure regarding the heterosexual transmission of HIV. By performing such a large demonstration in a largely heterosexual space, ACT UP members were able to reach a larger and more diverse audience than ever before (Carroll 2015).

By the beginning of the 1990s, the Women’s Caucus began fighting the medical establishment’s practice of largely ignoring women and people of color with AIDS. The Women’s Caucus worked with the American Civil Liberties Union to give women and people of color the right to be included in clinical drug trials (McGovern 2008; Stockdill 1997). Further, the caucus

⁶ Women’s Health Action and Mobilization (WHAM!) was a direct action activist organization established in 1989 in response to reproductive health issues of the time. Though mostly focused on reproductive issues and abortion, WHAM! Partnered with ACT UP in several protests, including the infamous “Stop the Church” action against St. Patrick’s Cathedral clergy’s stance on homosexuality and sex education (Schimke, Schreiner, and Mulliner 2018).

collaborated with Haslip and McGovern by channeling ACT UP dollars into protests and transportation for the plaintiffs to help pressure the CDC to expand its definition of AIDS. The slogan “Women don’t get AIDS. They just die from it,” (Appendix B) created by ACT UP affiliate and artist collective Gran Fury provided a nexus for organizing and generating a sizzling media buzz (Stockdill 1997, 10).

As part of its educational objective, the Women’s Caucus published an anthology called *Women, AIDS, and Activism*, making a point to provide comprehensive information about women and AIDS, with specific detail given to the varied cultural contexts in which AIDS presented itself, including a “chapter on prisoners, IV drug users, bisexuals, prostitutes, heterosexuals, lesbians, pregnant women, mothers, and teenagers,” (Carroll 2015, 152). The work alludes to the link between reproductive rights and AIDS activism, which continued to inform ACT UP demonstrations against Cardinal O’Connor’s abstinence-only sex-education campaign. Women’s reproductive rights group WHAM! joined ACT UP in this demonstration, though WHAM! members later recounted this controversial action as detrimental to the group’s reputation. This demonstration, called the Stop the Church action, continued to raise publicity as its members made headlines through die-ins and political theater.

ACT UP and Women’s Organization leaders “struggled to incorporate hundreds of new members into a community that had been based on close friendship ties and sought to reconcile diverging visions of its future,” (Carroll 2015, 155). Mindy Nass of WHAM! recounted that joining forces with ACT UP and its disruptive activism was effective insofar as the Stop the Church actions were concerned, but as a result, other community activists were reluctant to coalition build with WHAM! or ACT UP to enact social change. Partnering with ACT UP presented a “fundamental tension” between building broad movements while addressing the institutional homophobia and misogyny present in the legal and medical spheres of policy at the time (Carroll 2015, 159).

The focus of the Women’s Caucus on teach-in tactics closely echoed tactics used during Antiwar Opposition in the 1960s and 1970s. In fact, many of the organizers in the Women’s Caucus had prior experience in the Vietnam War Opposition, and the group’s tactics were reflective of this reality (Stockdill 1997). Additionally, many of the members of the Women’s Caucus and the Majority Actions Committee for people of color within ACT UP saw themselves as “heirs to a long tradition of civil disobedience struggles for social justice from the civil rights movements of the 1950s and 1960s to the gay and women’s liberation movements of the 1960s and 1970s,” (Baird, Davis, and Christensen 2009, 70-71). These activists saw the struggle against AIDS and its marginalization by mainstream media as symptomatic of a larger struggle against racism, homophobia, sexism, and classism, drawing tactical lessons from earlier social justice movements. The conflicting ideologies between the Women’s Caucus, Majority Actions Committee, and ACT UP’s general body led to eventual tensions and infighting over the organization’s priorities and direction (Stockdill 1997). Additionally, the volatile environment of AIDS activism meant that turnover rate for the organization was high, due to a combination of the emotionally draining nature of AIDS activism, loss of members due to the disease, and the movement of experienced activists from grassroots organizations to the ever-expanding and increasingly bureaucratic AIDS service industry (Stockdill 1997).

Gender Matters

Several former members of ACT UP described the unique relationship ACT UP had with gender, claiming the women of ACT UP “not only held powerful positions in ACT UP’s leadership

but were equals in the grassroots fight against AIDS—belying the popular perception of AIDS being a ‘gay man’s disease,’” (Banzhaf and Danzig 2015, n.p.). Many fondly remember ACT UP as a powerful space of psychological refuge for women supported by a community of LGBT peers and allies, providing a concrete political outlet for the community’s grief and anger. The activists of ACT UP often dated one another, allowing members to deal with the death that surrounded them while reclaiming their queer sexuality at a time when the dominant culture demonized such lifestyles. “Of course,” Banzhaf comments, “women always face consequences to un-thought-out sex,” arguing that “when confronted with real consequences, men had to listen to women in a different way,” (Banzhaf and Danzig 2015, n.p.). These women reveal a deeper image of women in ACT UP as thoughtful organizers with a long history of political experience. The women of ACT UP had a reputation for bringing intersectional issues to the social scene, giving activists strategic and tactical direction for demonstrations around women’s issues (Banzhaf and Danzig 2015).

Other members recounted that though women, and lesbians in particular, had held key leadership positions within the movement, in-fighting within the organization persisted, centering around race, class, and gender issues. The white male majority of ACT UP exhibited reluctance to admit the connection between racism and sexism in AIDS policy, as well as a tendency to ignore leadership contributions of women and people of color, even though these groups often had prior experience with activist movements (Stockdill 1997). This reputation contributed to frustrations among activists from marginalized communities, leading to conflicts around the focus for direct actions and tension among members (Stockdill 1997).

Though ACT UP maintained a “feminist-friendly” atmosphere, Women’s Caucus member Benita Roth identified unofficial social and organizational boundaries formed between members of the Women’s Caucus and the greater male-dominated activist network in order to enhance the group’s efficacy. In this way, the Women’s Caucus was able to act somewhere in-between the entirely gender-focused feminist groups and the better-established mixed-gender groups in the HIV activist scene (Roth 1998). Thus, the women of ACT UP were able to take control over their gender-specific agenda and advocate for themselves, calling upon the male members for additional support. This dichotomy reinforced gender differences and allowed women to promote their own agendas through direct actions focused on women’s needs regarding AIDS, perhaps at the expense of greater male participation and advocacy (Roth 1998).

Carroll (2015) traces the roots of modern grassroots activism back to the tactics used during the civil rights movement and the War on Poverty. He argues that earlier nonviolent movements inspired contemporary Community Action Programs through both methodology and rhetoric, enabling these movements to improve the realities of their members’ day-to-day lives while intensifying their means to bring about serious policymaking.

Women in intersecting social movements have walked the line between creating separate movements which focus on gender and working within the framework of larger movements, much like women with ACT UP and the broader movement around AIDS. Women activists tend to separate themselves to some extent, like the Women’s Caucus did, though further in-fighting within women’s groups and between these groups and larger organizations poses an existential threat for these very groups. Activists often lie at the intersections of sister movements, yet many activist women “have chosen to work separately for a time, with the goal of eventual integration with other activists when there is a sufficient basis of unity,” (Meyerding 1997, 573). ACT UP, the Women’s Caucus, WHAM!, and the HIV Law Network were able to work together as a unified front even though their politics would eventually diverge.

Who Gets A Say?

Due to mounting global outcry and political pressures from a changing Presidential administration, the CDC announced in September of 1992 that it would expand its definition of AIDS. For six weeks, CDC officials met with the HIV Law Project workers, medical experts, and other representatives of the seropositive community. On her deathbed, Haslip sent a message to be read at the conference hearing, stating, “This is only happening because of us, and you let us die,” (McGovern 2008, n.p.). This moving message reflects the ethical imperative of policymakers and government agents to act quickly to address the needs of HIV and AIDS-positive community members. McGovern also described her frustration during the negotiations, as each party involved had different goals and compromises in mind (2008).

The CDC initially considered expanding the definition to include those with CD4 cell counts fewer than 200 (McGovern 2008). Though this expansion would be an important step in getting diagnoses for individuals who were dangerously immunocompromised but did not fall under the former definition, it failed to take into account errors with the CD4 count testing procedures. Additionally, individual variation meant that some people with lower CD4 cell counts could remain relatively healthy while others with counts above 200 were still falling seriously ill. Healthcare providers and bolder activists urged McGovern to push for further expansion to include common women’s infections like cervical cancer, recurrent bacterial pneumonia, and pulmonary tuberculosis (McGovern 2008). They reasoned that the CD4 counts were not enough since doctors might never test women with these opportunistic infections without their explicit inclusion in the definition (McGovern and Manlowe 1997).

The success of *S.P. v Sullivan* in pushing the Social Security Administration to revise its disability diagnostic procedures for AIDS brought in more support from larger AIDS and LGBT groups in Washington. Though their financial and network support initially helped the cause, McGovern soon found that larger, more institutionally-aligned AIDS groups in Washington were invited to the meetings with the CDC instead of the original ACT UP volunteers and the seropositive women involved in the case. Several ACT UP activists even handcuffed themselves to the Washington representatives in a display of outrage at one infamous meeting (McGovern 2008).

During the final weeks of discussions with the CDC, McGovern asked the seropositive women for their opinions on the definition. As many of the plaintiffs were starting to die, they had become desperate for a quick and decisive change. Many feared that further pushing from activists would cause the legal process to break down and ultimately delay the expansion of the definition. In a 2007 interview with Sarah Schulman, McGovern recounts that:

It was very hard for me to make a judgment about how far to push, when you were going to lose everything. And in some senses, a lot of times, the positive women were really thinking about how many people would lose benefits and how many people would die if we pushed too far (2008, n.p.).

With time running out for her clients, McGovern faced a harrowing dilemma. Though the inclusion of a CD4-based definition would be a quicker solution for her clients, activists pushed more ambitious agendas to expand the definition to specifically include women’s opportunistic infections in the definition as a political statement about inclusion of women in medical conceptions of the disease. Though McGovern still had a seat at the table, her poor and HIV-positive clients were increasingly excluded from the proceedings. How can policy-shapers like

McGovern and the HIV Law Project balance the conflicting demands of activists, affected communities, and stakeholders while working within bureaucratic institutions like the CDC? Should activists compromise in order to accomplish important goals, or should they push for sweeping change?

Epilogue

The CDC officially recognized the unique clinical manifestations of AIDS in women on January 1, 1993 (Rodriguez and Manlowe 1997). Bacterial pneumonia and gynecological conditions were added to the surveillance list of infections for AIDS in order to determine patient eligibility for disability programs, housing, research, and allocation of government funds (Kates et al. 2013). In *Beyond Reproduction*, Baird, Davis, and Christensen (2009) list major achievements of the women's health care movement in the 1990s, all of which had major impacts on HIV-positive women:

- Passage of the 1993 National Institutes of Health (NIH) Revitalization Act that mandates the inclusion of women and minorities in research funded or performed by NIH;
- Change in the Center for Disease Control's (CDC) definition of AIDS-related symptoms to include conditions more appropriate for women, as well as an increase in NIH funds for research devoted to AIDS-related issues in women;
- Increased public attention to and medical awareness of domestic violence as a healthcare issue, passage of the Violence Against Women Act (VAWA), and increased government funding for research on and prevention of domestic violence.

Tragically, Katrina Haslip, "S.P.," and all but one of the plaintiffs passed away without seeing the benefits of their brave work (The New York Times 1992). Though the seropositive community of women suffered great losses before women were included in AIDS research, subsequent generations of women now benefit from the expanded definition, research, and disability policy (McGovern 1994).

In addition to the HIV-positive women involved in *S.P. v. Sullivan*, by the mid-1990s, many of ACT UP's most influential figures had died from AIDS. This tragedy coupled with the release of new drugs and therapies for HIV led to a steady decline in ACT UP involvement through the mid-to-late 1990s. Though the fight to eradicate AIDS is ongoing, many of the most fervent chapters disbanded due to optimism for the future, a lack of interest, and changing priorities among HIV-positive communities.

Infighting about the direction of future efforts caused several groups to break off from the organization, employing ACT UP's political theatrics to fight homophobia and heterosexism. Groups like Queer Nation and the Lesbian Avengers were notable offshoots, replacing the unified gay liberation aspect of the AIDS advocacy organization. While many cities maintain their local chapters, ACT UP lost its political might and relevance (Kaplan 2001). Rodriguez and Manlowe (1997) note that in 1994, "more than 14,000 new AIDS cases were diagnosed in women, representing 18 percent of all new cases and a dramatic increase in incidence from the 534 cases and 8 percent of total cases reported nine years earlier" (n.p.). Though this uptick in cases might seem disheartening for those fighting the HIV/AIDS epidemic, the sheer increase in diagnoses shows just how exclusive the CDC's definition had been. Thanks to the work of Katrina Haslip, Terry McGovern, and the ACT UP Women's Caucus, thousands of women were now considered and had access to federal funding, research, and disability benefits. Though these groups became increasingly fractured due to changing political realities, they were able to work

together to achieve successful policy and attitude change in the United States that saw ripple effects worldwide. Foregrounding of marginalized voices through groups like the Women's Caucus and the HIV Law Network allowed their activism to be enacted more authentically, leading to tangible change that made a difference in the lives of the poorest and most medically underserved women. This case highlights the tension between achieving larger political goals and achieving smaller gains that can immediately benefit stakeholders. This case highlights a grassroots approach to legal advocacy that endeavored to center the needs of PWAs in legal and direct action.

References

- Amaro, Hortensia. 1995. "Love, Sex, and Power: Considering Women's Realities in HIV Prevention." *American Psychologist* 50 (6): 437–47.
- Baird, Karen L, Dana-Ain Davis, and Kimberly Christensen. 2009. *Beyond Reproduction: Women's Health, Activism, and Public Policy*. Madison, New Jersey: Fairleigh Dickinson Univ Press.
- Banzhaf, Marion, and Risa Denenberg. 1990. "Unique Aspects of HIV Infection in Women." In *Women, AIDS, and Activism*, ed. Banzhaf, Marion. Boston, Massachusetts: South End Press, 39–43.
- Banzhaf, Marion, and Alexis Danzig. 2015. Interview by Zaahira Wyne. "The Women Who Fought AIDS: 'It Was Never Not Our Battle'." August 28. https://broadly.vice.com/en_us/article/mbqjqp/the-women-who-fought-aids-it-was-never-not-our-battle (Accessed November 2, 2018).
- Carroll, Tamar W. 2015. *Mobilizing New York: AIDS, Antipoverty, and Feminist Activism*. Chapel Hill, North Carolina: University of North Carolina Press.
- Clark, Judy, and Kathy Boudin. 1990. "Community of Women Organize Themselves to Cope with the AIDS Crisis: A Case Study from Bedford Hills Correctional Facility." *Social Justice* 17(2): 90–109.
- Code of Federal Regulations: 1949-1984*. 1983. U.S. General Services Administration, National Archives and Records Service, Office of the Federal Register.
- Erni, John Nguyet. 1994. *Unstable Frontiers Technomedicine and the Cultural Politics of "Curing" AIDS*. Minneapolis, Minnesota: University of Minnesota Press.
- Gran Fury. 1991. "Women Don't Get AIDS. They Just Die from It. (Poster)" New York Public Library Digital Collections. <http://digitalcollections.nypl.org/items/510d47e3-5399-a3d9-e040-e00a18064a99> (Accessed May 18, 2019).
- Hammonds, Evelyn M. 2009. "AIDS the Secret, Silent, Suffering Shame." In *Still Brave: The Evolution of Black Women's Studies*, eds. James, Stanlie M., Foster, Frances Smith, and Guy-Sheftall, Beverly. New York, New York: Feminist Press, 268–80.
- Jennings, M. Kent, and Ellen Ann Andersen. 1996. "Support for Confrontational Tactics among AIDS Activists: A Study of Intra-Movement Divisions." *American Journal of Political Science* 40 (2): 311–32.
- Kaplan, Esther. 2001. "The Mighty ACT UP Has Fallen: The Philadelphia Story."

- November 1. <https://www.poz.com/article/The-Mighty-ACT-UP-Has-Fallen-The-Philadelphia-Story-1278-7383> (Accessed November 5, 2018).
- Kates, Jen, Tina Hoff, Sarah Levine, Alicia Carbaugh, and Carolina Gutierrez. 2013. *A Report on Women and HIV/AIDS in the US*. <https://kaiserfamilyfoundation.files.wordpress.com/2013/04/8436.pdf> (Accessed November 4, 2018).
- McGovern, Terry. 2008. Interview by Sarah Schulman. "076." ACT UP Oral History Project. <http://www.actuporalhistory.org/interviews/images/mcgovern.pdf> (Accessed November 2, 2018).
- McGovern, Theresa M. and Jennifer L. Manlowe. 1997. "Barriers to the Inclusion of Women in Research and Clinical Trials." In *The Gender Politics of HIV/AIDS in Women: Perspectives on the Pandemic in the United States*, eds. Nancy Goldstein and Jennifer Manlowe. New York, New York: New York University Press, 63-73.
- McGovern, Theresa M. 1994. "S.P. v. Sullivan: The Effort to Broaden the Social Security Administration's Definition of AIDS." *Fordham Urban Law Journal* 21 (4): 1093-1096.
- Meyerding, Jane. 1997. "Women and Nonviolent Action in the United States since 1950." In *Protest, Power, and Change: An Encyclopedia of Nonviolent Action from ACT-UP to Womens Suffrage*, eds. Robert S Powers. New York, New York: Taylor & Francis. 569-73.
- Navarro, Mireya. 1992. "An AIDS Activist Who Helped Women Get Help Earlier." *The New York Times*, <https://www.nytimes.com/1992/11/15/weekinreview/conversations-katrina-haslip-an-aids-activist-who-helped-women-get-help-earlier.html> (Accessed May 17, 2019).
- Patton, Cindy. 1994. *Last Served? Gendering the HIV Pandemic*. London, United Kingdom: Taylor & Francis.
- Rodriguez, Bill, and Jennifer L. Manlowe. 1997. "Biomedical Models of HIV and Women." In *The Gender Politics of HIV/AIDS in Women: Perspectives on the Pandemic in the United States*, ed. Nancy Goldstein. New York, New York: New York University Press, 25-42.
- Roth, Benita. 1998. "Feminist Boundaries in the Feminist-Friendly Organization." *Sociologists for Women in Society* 12 (2): 129-45.
- Schimke, Rachel, Maggie Schreiner, and Heather Mulliner. 2018. "Guide to the WHAM! (Women's Health Action and Mobilization) Records TAM.162." http://dlib.nyu.edu/findingaids/html/tamwag/tam_162/bioghists.html (Accessed May 17, 2019).

Stockdill, Brett C. 1997. "ACT-UP (AIDS Coalition to Unleash Power)." In *Protest, power, and change: an encyclopedia of nonviolent action from ACT-UP to Women's Suffrage*, ed. Roger S Powers. New York, New York: Taylor & Francis, 9–10.

The New York Times. 1992. "Katrina Haslip Dies; AIDS Worker Was 33." *The New York Times*, <https://nyti.ms/2FJ1186> (Accessed May 18, 2019).

Wilder, Terri. 2012. "A Timeline of Women Living With HIV: Past, Present and Future – Introduction." June, <http://www.thebody.com/content/16568/a-timeline-of-women-living-with-hiv-past-present-a.html> (Accessed March 22, 2019).

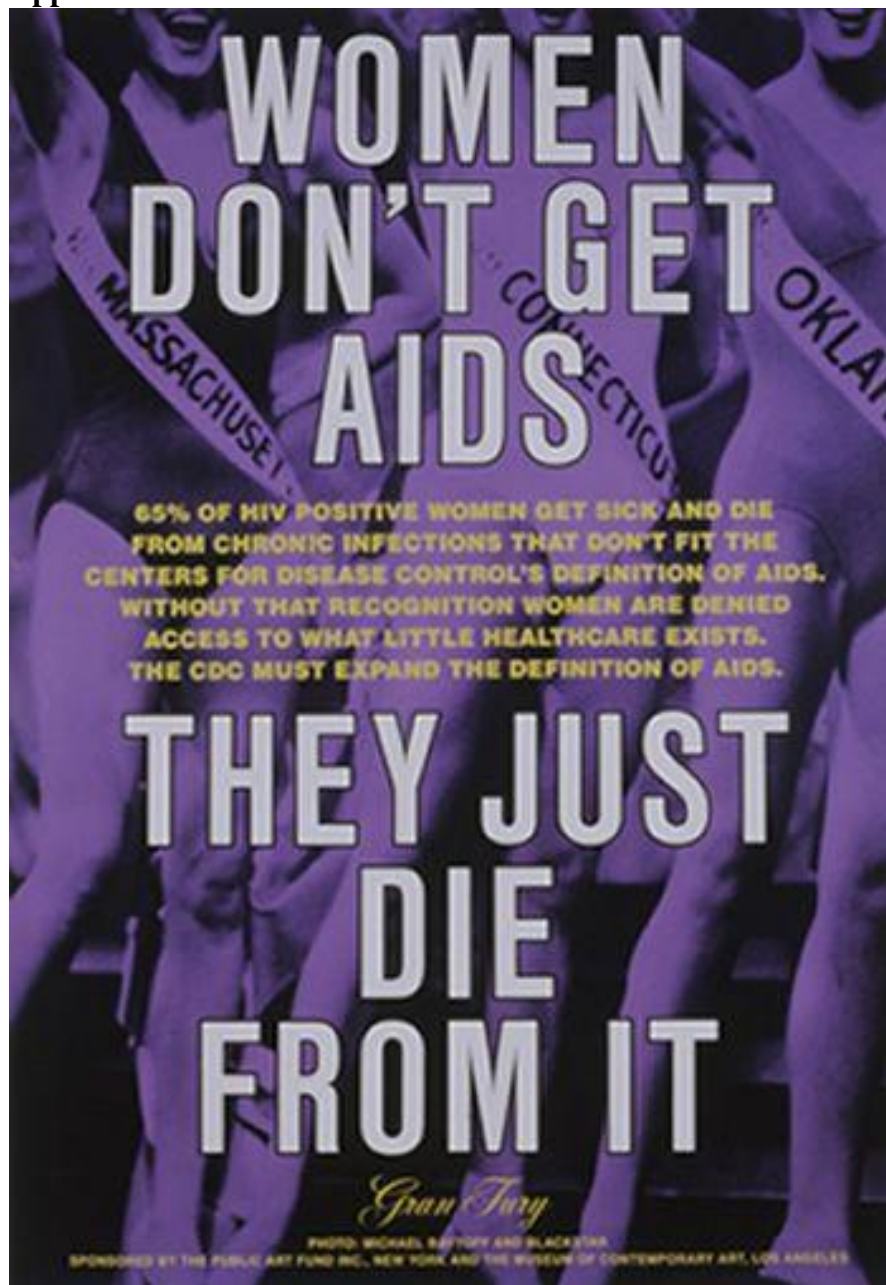
U.S. Dept. of Health and Human Services. 2019. "AIDS Info Glossary". https://aidsinfo.nih.gov/contentfiles/glossaryhivrelatedterms_english.pdf. (Accessed March 22, 2019).

Appendix A:

Compiled from “A Timeline of Women Living with HIV: Past, Present and Future” (Wilder 2012).

1981	The first case of GRID, later renamed to AIDS, is reported. Five women are among those diagnosed.
1982	The women diagnosed with this illness are classified under the risk category of "prostitutes." Reports are published about male and female drug users, as well as people receiving blood transfusions being diagnosed with AIDS.
1983	The CDC adds female sexual partners of men with AIDS as a "risk group."
1984	A diagnostic blood test for HIV is developed.
1985	For the first time, a woman is admitted to the AIDS ward at San Francisco General (Ward 5B).
1986	Women represent seven percent of U.S. AIDS cases. Marie St. Cyr, a Haitian-born social worker, becomes the first director of the New York-based Women and AIDS Resource Network (WARN) after it is formed by several women living with and affected by HIV.
1987	13.5% of NIH money is dedicated to women's health issues. ACT-UP is founded. Women are excluded from HIV trials unless they are on the birth control pill or IUD
1988	A <i>Cosmopolitan</i> magazine article written by a psychiatrist tells women that they are not at risk for AIDS if they have “normal sex” and “healthy vaginas.” Women named fastest growing population with HIV.
1989	Rebekka Armstrong, former Playboy Playmate, tests HIV positive. HIV Law Project is founded by Theresa McGovern.
1990	The First National Women and HIV Conference is held. ACT-UP spearheads a massive protest at the Centers for Disease Control in Atlanta to expand AIDS definitions to include women-specific opportunistic infections. National "Speak Out" by women with AIDS is held in Washington, DC to protest the Social Security definition of disability. Elizabeth Glaser, a woman living with HIV, speaks at a House subcommittee hearing on pediatric AIDS, where she is praised for convincing the formerly unresponsive Ronald Reagan to do a public service announcement on pediatric AIDS.
1992	A full-page ad in <i>The New York Times</i> reads "Women Don't Get AIDS. They Just Die From It." Over 300 grass-roots groups signed the ad.
1993	The CDC expands the definition of AIDS to include: bacterial pneumonia, <u>TB</u> and stage III cervical cancer. Recurrent vaginal <u>candidiasis</u> (yeast infections) also added as a symptom of HIV.

Appendix B:



Gran Fury (Artist Collective) "Women Don't Get AIDS" (1991)