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LITIGATING RISK

The Law and Politics of Disease in the Administrative State

In October 1990, lawyer and activist Terry McGovern filed suit against Health and Human Services (HHS) in an effort to broaden the Social Security Administration's (SSA's) definition of AIDS. *S.P. v. Sullivan*, and the activism surrounding it, would become a key milestone in the feminist fight to demand recognition in the struggle against AIDS.[1] The case challenged the denial of Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) for women suffering from AIDS-defining illnesses, whose symptoms were excluded from the US Centers for Disease Control and Prevention (CDC) definition of AIDS.[2] McGovern, the plaintiffs, and advocates had three goals emanating from the litigation and advocacy surrounding it. First, to force the SSA to delink its disbursement of benefits and medical care from the narrow definition of AIDS being utilized by the CDC. Second, to mandate that the SSA broaden its understanding of what constituted a disabling illness in the context of AIDS (to include female-specific illnesses). And third, to utilize the litigation as another opportunity to pressure the CDC to change the medical definition of AIDS.

McGovern was a new lawyer. As she was preparing for litigation, she often wondered if she was in over her head.[3] But after witnessing other lawyers spray their office chairs with disinfectant when an AIDS patient would depart, dying and desperate, she knew there were few attorneys willing to take cases for people living with HIV.

For her clients and the many advocates supporting the lawsuit, litigation provided a key opportunity to force the government to respond *in court* to the inadequacies of the SSA's process for providing financial support and medical care to people living with AIDS.

While the lawsuit travelled through the courts, the ACT UP Women's Caucus and advocates from a range of organizations, including Life Force: Women Fighting AIDS and SisterLove, sought to hold government leadership accountable. They did this by mobilizing large-scale grassroots efforts alongside state-centered advocacy: writing letters, protesting outside of government offices, participating in notice and comment periods, and introducing bills to the legislature.

This chapter follows the litigation and advocacy of ACT UP, lawyers, and of women living with HIV from 1990 to 1994, as they slowly turned the heads of CDC experts toward women's issues in the epidemic, resulting in a new medical definition of AIDS. In documenting this story, the chapter challenges a core idea in new literature on law, health, science, and technology, which often describes law as lagging behind scientific progress. The story of women and AIDS argues that this oft-repeated thesis mischaracterizes the relationship between law, social movements, and science. Rather, this chapter argues that law and advocacy can alter a scientific and medical landscape. For feminists organizing in the context of AIDS, the belief that law and advocacy can alter science (rather than simply rely on it) is central to the success of redistributional efforts in the context of public health activism.

For feminists, making the connection between law, science, and redistribution was especially important in the time period in which this feminist fight was playing out. As documented by historian of medicine Keith Wailoo, the Reagan administration was explicit about the distributional relationship between medical expertise and disability benefits. In mandating that physicians validate disability claims, the Reagan administration ensured that the denial of benefits was the product of purportedly objective expertise. This move divested power from potentially sympathetic administrative judges.[4] And, for those paying close attention, it made medical objectivity part of the target of activism.

This political environment – in which purported medical objectivity could be the foundation for contracting the welfare state and cutting people off of disability services – provides the backdrop against which *S.P. v. Sullivan* takes place. Advocates realized that to change the distribution of resources, they had to change the science itself. Importantly, taking on purportedly objective ideas generated through scientific and medical means was not foreign to the specific group of advocates in this story: that had been a project of the feminist movement since at least the 1960s. With AIDS, the feminist critique of science and medicine had a new home and a new group of advocates carrying the project forward: welfare lawyers and AIDS activists. This chapter argues that litigation and advocacy can alter scientific understandings of disease, and, in turn, change the core distribution of goods and services related to healthcare.

FEMINISTS LITIGATE AIDS

The *S.P. v. Sullivan* plaintiffs exemplified the types of issues faced by women in the epidemic, from the gynecological manifestations of the virus, the repeat denials of SSA benefits, and the consequences for their children. Sandra[5] was a twenty-three-year-old Latina living in Manhattan. Her two children were in foster care. She tested HIV positive in 1989 and applied for SSI because of increasingly worsening pelvic inflammatory disease, weight loss, headaches, vomiting, shortness of breath, and dizziness. Her application was denied twice, despite her hospitalization. In August of 1990 Sandra had a hearing. She submitted medical reports documenting the ongoing issues of pelvic inflammatory disease, anemia, weight loss, and vomiting. She also had a T-Cell count of 200–300 indicating that her immune system was depressed. She was denied SSA benefits again. At the time the litigation began she was waiting to get a rehearing. Sandra's two children had been taken to foster care due to her "inability to afford better living conditions."[6]

The plaintiff Barbara,[7] a thirty-nine-year-old African American woman, applied for disability benefits in April 1989, providing evidence from a physician that she was unable to work. Barbara lived with her three minor children, one of whom was a three year old who also had HIV. She suffered from numerous gynecological illnesses. Barbara required a home healthcare worker to assist in caring for her and her children. She was denied SSI and SSDI. Barbara reapplied but upon reconsideration her applications were also denied.[8]

Monica was thirty-one years old and Latina. She applied for disability insurance benefits on July 20, 1988 because she had been disabled since May 2, 1984 by a combination of impairments including chronic, intractable gynecological complaints.[9] Her treating physicians had informed her in 1987 that she was infected with HIV. Monica struggled with a wide range of gynecological issues including a ruptured ovarian cyst, tubal infection, ovarian cancer, and undiagnosed vaginal bleeding. The SSA denied Monica's initial application and denied her again at reconsideration. She was unable to attend her last hearing because she was hospitalized for attempted suicide. The adjudicators found Monica disabled but said that her disability only began with her HIV diagnosis. She appealed the decision and was waiting for another hearing at the time the lawsuit was filed. In the meantime, she used her initial benefits to rent an apartment. She'd been sleeping on her parents' floor until then. She hoped that the additional benefits would aid her living situation as well as her family's.[10]

Feminist ideas, shaped by the broader feminist AIDS struggle, drove the litigation and the claims for relief. The first claim was that the policies, standards, practices and procedures of the SSA were arbitrary, capricious, and contrary to the Social Security Act because plaintiffs were being denied disability benefits without meaningful assessment of relevant medical evidence and in turn were experiencing harmful delays, considering the likelihood of death, in receiving disability benefits and medical care. The second claim was rooted in the Due Process Clause of the Fifth Amendment. Plaintiffs argued that there was no meaningful assessment of the determinations made regarding the plaintiffs' ability to work creating a harmful delay in the award of disability benefits. Third, plaintiffs argued that the policies, standards, and procedures violated the Equal Protection Clause of the Fifth Amendment because they had created and maintained two classification systems for people with HIV-related impairments – those included in the CDC definition and those not included in the CDC definition. In turn, the plaintiffs argued that the designation of people as disabled was arbitrary and irrational. Fourth, and related, the plaintiffs argued an equal protection violation of the subclass of women, because "on information and belief the Secretary, acting with a discriminatory purpose, has maintained a definition of disability which excludes a class of women by excluding the most common manifestations of disabling HIV-infection in women."[11] Women, they also argued, were being disparately impacted due to the secretary's failure to recognize as disabling any of the most common manifestations of disabling HIV infection in women. The plaintiffs claimed that the policies, standards, and procedures of the SSA also disparately impacted members of racial minority groups because many of the common manifestations of disabling conditions found in

African American and Latinx persons were not on the enumerated list of illnesses.[12] As articulated in filings:

> Since it [the CDC] began its epidemiological surveillance of the epidemic, the CDC has focused its research on the segment of the United States population in which the HIV epidemic was first manifested: a predominantly affluent, predominantly white group of male homosexuals. Thus, most of the epidemiological data collected by the CDC reflects the opportunistic infections which were typical of that particular population subgroup.
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> The CDC has been publicly criticized for its failure to study or fund studies of HIV infection in women, children, and intravenous drug users, and poor people, and for its consequent exclusion from its definition many of the most common manifestations of HIV-related disease in these populations.[13]

The fifth claim for relief harkened back to the failure of the SSA to provide an opportunity for the public – through notice and comment – to respond to the proposed rules in violation of the Administrative Procedures Act.[14]

These claims accompanied demands for relief that included benefits for women while they waited for decisions, and a directive to disability adjudicators highlighting the failures of the SSA list of impairments. In order to provide fair process to the plaintiffs, they demanded that instructions be issued to adjudicators of disability claims acknowledging that HIV may manifest in ways other than those described on the CDC list. They sought that the adjudicators of disability hire medical experts who were informed about clinical manifestations of HIV-related impairments, and train others to evaluate HIV-related disability claims.[15] The plaintiffs also asked that presumptive disability be paid to any and all claimants with proof of infection with HIV "and a treating physician report reflecting that the claimant is disabled or unable to work."

The day the lawsuit was filed, the ACT UP Women's Caucus, ACT UP COSTAS, and ACT UP DC planned a protest in Washington, DC.[16] The organizers were thorough in their planning: organizing childcare for women participating in the protest and ensuring lawyers were on standby in the event that individuals were arrested. Information was distributed to protestors clarifying that those people who were arrested for civil disobedience could be taken to custody by Federal Protective Services or DC Metropolitan Police. As a best-case scenario, they hoped to only receive citations.[17] A few weeks before the protest, a press release announced that "hundreds of AIDS activists from around the country will besiege the Department of Health and Human Services in Washington, D.C. on Tuesday October 2nd, to demand that women with HIV/AIDS be given the same immediate (presumptive) disability benefits now given to men."[18]

Members of ACT UP New York came down from the city to Washington, DC in buses and stayed at the Carlyle Suites Hotel. Linda Meredith, member of the ACT UP Women's Caucus and ACT UP COSTAS, served as point person for the protest.[19] She had been active on AIDS issues after hosting several AIDS activists at the Democratic National Convention while living in Georgia.[20]

As was often the case at ACT UP protests, a background sheet was provided to all participants which explained why the protest was happening and what people should be angry about. For this protest, the backgrounder explained that the definition of AIDS excluded women and that women should also receive presumptive benefits from the SSA. It noted that the time between diagnosis and death was approximately twenty-seven weeks for women, a timeline that made the SSA responsible for "killing women" by forcing them to undergo an unnecessarily long process to receive a disability diagnosis.[21] Advocates met at 9 AM at the First Congregational Church in Washington DC and departed for the protest at HHS a few hours later.

Hundreds of activists arrived on the doorstep of HHS on October 2, 1990. The demands at the protest matched those of the lawsuit. Feminist activists and ACT UP members arrived at the building holding signs that read "Women Don't Get AIDS. They Just Die From It" and "Women and AIDS: Dead But Not Disabled." Flyers produced by ACT UP DC stated "SSA operates with a 60 billion surplus, a surplus that has been raided by the Reagan and Bush administrations to decrease the Federal deficit. These policies send a clear message that women's lives are expendable."[22] The flyers emphasized the gender and racial differences between HIV in men and in women in the epidemic: "The CDC definition of AIDS is based on symptoms seen in white males, and ignores the fact that women with HIV/AIDS get chronic vaginal candidiasis, pelvic inflammatory disease, cervical cancer, liver disease, endocarditis, tuberculosis and septicemia. Using their definition, 65% of women with HIV/AIDS die without a CDC diagnosis of AIDS."[23]

A chant sheet was distributed to each of the activists. The chants targeted Louis Sullivan, head of the HHS at the time. The slogans spoke directly to changing the CDC definition: “SSA has got to pay, we need benefits today!”; “Women with AIDS need disability, change the rules for eligibility!”; “Killing by omission, change the definition!”; “Racist, sexist, anti-dyke, Louis Sullivan, take a hike!”; and “Presumptive disability for women who have HIV!”[24]

By this time, Katrina Haslip, who had been organizing women with HIV in prison, was now on probation. Despite her risk of violating probation by traveling to Washington, DC, she showed up to the protest.[25] There she and Terry McGovern, despite having communicated for years, met for the first time. Haslip gave testimony at the protest. She described how the SSA had only given her eighteen dollars in cash and thirty-three dollars in food stamps. At the time she was thirty-one years old and her T-Cell count was very low: forty-seven. By all counts this would qualify her as having crossed the threshold from HIV to AIDS. She told the crowd:

> The reality is that women have real disabling symptoms of HIV that aren’t the same as gay white men. Our symptoms can be early signs of the progression of AIDS. I want this to be acknowledged before I develop more severe symptoms and before death. The definition has to be expanded so that the opportunistic infections women get are included, and so that women can be entitled to the same disability benefits.[26]

Iris Delacruz also spoke. Like Haslip, Delacruz had been in Bedford Women’s Prison. She was a white thirty-seven-year-old woman who was also living with HIV. She spoke about being an intravenous drug user with a repeated history of pelvic inflammatory disease. She was not a likely candidate for pelvic inflammatory disease as she had no prior sexually transmitted infections (STIs) or gynecological problems. Despite being an active drug user and having pelvic inflammatory disease, she was never given an HIV test. She had been organizing women with HIV to demand better from medical and public health agencies.[27]

Eighteen people at the protest were arrested. As the protestors were chanting, and the lawsuit was filed, Congressman Ted Weiss of New York made a statement in the House of Representatives. Like the advocates, plaintiffs, and lawyers, he called for the SSA to remedy the inequalities faced by women in the epidemic. Weiss spoke to the need for a more accurate definition of AIDS to ensure that women are not being excluded from the response to the epidemic.[28]

Together the litigation and activism were paying off. As described by McGovern:

> I think the combination of having the litigation and the demonstration and all this ACT UP work that had gone on finally started to scare the government a bit. Because they had to respond in court. And they could see that … all this ACT UP work that had gone on had really, really kind of big allies were developing at this point. I mean, the American Medical Association came in on the lawsuit, which was crazy, unbelievable. ACT UP had gotten a lot of very prominent groups to sign on to this stuff. So, I think they really started to get very nervous. And I think in terms of positive women, suddenly people were seeing positive women as leaders, also. Who were saying I've been denied disability. This is, so it wasn't just generalized complaints. There were specific things that needed to be changed. So I think it was an extremely powerful moment in this whole struggle.[29]

There was a gender dynamic to the activism itself. The men involved in ACT UP had education, access, and skills. For McGovern, working with poor women of color meant that her clients were struggling. They understood the hurdles they faced but they did not have the political savvy, nor did they look like the men they were negotiating with. But, despite the vast differences in life experience, many of the men in ACT UP supported the women's advocates as they staged protests and fought for the definitional change.

As the multipronged effort continued, the case and activism garnered national attention, shifting the public conversation about AIDS away from the perspectives of skeptics and toward the advocates arguing that women had long been contracting HIV and constituted a risk group. The *Baltimore Sun* ran an article the day after the lawsuit was filed with the headline "U.S. said to ignore women with AIDS." Phyllis Sharpe, a mother of six who was living with HIV, and a plaintiff in the litigation, was quoted in the article: "You have to be half dead to be declared disabled."[30] *USA Today* ran a short article with an image of two ACT UP activists, David Falcone and Kathy Chou, in which he held her head as she enacted sickness.[31]

CONFRONTING THE CDC

Momentum was building. On November 17, 1990, the ACT UP Network (the coordinating body of ACT UP chapters from throughout the United States) called for a week of outrage from November 26 to December 4. To mark it ACT UP planned a series of protests and actions around the country related to women and girls.

Two days later, on November 19, members of ACT UP met with CDC representatives in Atlanta. The conversation was transcribed by ACT UP. The ACT UP members present included Katrina Haslip, Tracy Morgan, Chip Rowan (from ACT UP Atlanta), and Maxine Wolfe.[32] Haslip was also there in her capacity as a representative of Life Force. CDC representatives included Gary Noble, Deputy Director of the HIV Unit at the National Institutes of Health (NIH), and Ruth Berkelman, Chief of the Reporting and Analysis Section of the CDC.

Advocates began the meeting by stressing the need for more attention on issues related to women. Haslip delivered a presentation describing the opportunistic infections women were experiencing. Morgan presented available research on the symptoms of HIV as they manifested in women. Wolfe then raised the issue of the CDC's definition and the exclusion of women from AIDS diagnoses.

Following the ACT UP presentations, CDC staff responded. The activist transcript reflected both tensions and convergence in the issues that were raised by advocates. ACT UP members argued that sexism and homophobia were precluding the CDC from taking up women's issues. Gary Noble responded to this claim. He denied that these were problems of the CDC staff working on HIV, but acknowledged that "culture" makes it impossible to escape the possibility that sexism and homophobia are present. All of the advocates and experts present agreed that women were not being appropriately captured in the current surveillance system.[33] For the ACT UP activists, there was a simple answer to structural bias against women and racial minorities: Expand the AIDS definition to include gynecological issues. This would increase the number of diagnoses among women and have the corollary effect of allowing women to get presumptive benefits from the SSA. The CDC was concerned that expanding the definition might have complicated repercussions. First, because this was a surveillance definition it hoped to have the definition as tight as possible: no false positives, no false negatives. Expanding the definition could produce numerous false positives. And, some of the failures of surveillance weren't due to the CDC definition but to medical practice, which itself introduced many errors into the AIDS diagnosis.[34] The CDC had opted for the most cautious strategy: to only count the most severe manifestations of AIDS. Advocates recognized the cost of this: While a narrow definition would create few false positives, it could create many false negatives, leaving people who had

AIDS without a diagnosis. It was a cost–benefit analysis justified by the goal of the CDC's efforts: to surveil disease correctly.[35] By erring on the side of producing false negatives instead of false positives the CDC could more accurately claim that it was taking a cautious approach to counting AIDS cases. There was pressure on the CDC by the federal government to get the numbers exactly right. Importantly, a broader definition would produce confusion among scientists and medical professionals attempting to track trends in the spread of the virus.[36] Ultimately, the CDC had to retain its integrity as an institution grounded in evidence and science – one resistant to political pressure. While the CDC admitted that the evidence base on HIV was thin, it held that it was even more so for women. It made the choice to restrict the definition to only what appeared to be the clearest symptoms associated with immunocompromised people, leaving women out.[37] The CDC argued that to add on illnesses without an evidence base, including those like pelvic inflammatory disease or candida vulvovaginitis, had the potential of leading to an upward swing in AIDS diagnosis. Because these conditions were not only manifesting in women with HIV, this could result in many false positives. Retaining control over surveillance was key to preserving the integrity of the CDC.[38]

For activists at the meeting, the reticence of the CDC staff to consider altering the definition to include women at the cost of institutional legitimacy was a symptom of the very problem they had diagnosed: sexism. They argued in response that the CDC did not wait to gather necessary evidence about AIDS in gay men or children.[39] Nor did the CDC hesitate to craft early definitions of AIDS based on little evidence. Advocates argued: "Nobody waited for years to do those studies for gay men; nobody did it for children …. This is very very typical – white men do not have to wait[40] to be included, everyone else needs proof, beyond a shadow of a doubt."

Activists demanded that the CDC explain how it was that early definitions of AIDS, based on little data, were pulled together quickly, while now further into the epidemic women were not benefitting from an aggressive response to AIDS.[41] As one advocate argued,

> All I keep hearing and I still hear the same thing, that because these things appear in women, and because they just get worse when women are immunosuppressed, they shouldn't be in the definition of AIDS. And, that you are going to scare a lot of "nice" women who get these infections anyway but I know that the "not nice women" are going to

> die …. Let's be real. We don't know any more about the male opportunistic infections that are in there. But the criteria you are setting for putting in indicator and opportunistic infections is a double standard. You have not required that from other indicator diseases or opportunistic infections and it's just for women that you are requiring it.

CDC staff held their ground. They argued again that the illnesses associated with HIV in men were all a result of immune system suppression. Thus, there was reason to believe, given the appearance of the illness, that it was being caused by HIV especially when taking into account context.[42] The CDC staff felt this was distinct from the claims being made by women's rights advocates because the conditions they sought to add to the CDC definition of AIDs were not necessarily linked to immunosuppression but instead to cancers and illnesses that could appear in any woman regardless of her HIV status. To this, advocates pressed that women who had HIV were not experiencing regular manifestations of pelvic inflammatory disease or other illnesses. Instead, women with HIV were experiencing more severe forms and repeated illness which could largely be accounted for due to HIV suppression of the immune system.

Finally, while CDC experts were sympathetic to the fact that the SSA was using the CDC definition for disbursing benefits, including access to medical care, it insisted that the CDC was not responsible for care – only for surveillance. The SSA was responsible for ensuring that people were receiving care, and the CDC punted all issues of care to the SSA – even though the CDC had repeatedly asked the SSA to stop using its narrow AIDS surveillance definition to disburse benefits.

The meeting ended with little resolution. Angry at the lack of progress, an unidentified activist living with HIV told the CDC staff, "You would save yourself an awful lot of trouble if you just got together all of these clinicians and just asked them what they were seeing. I hold each of you personally responsible for the death of every woman with HIV I know, including myself."[43]

Continuing pressure on the CDC a few weeks later, on December 1st through 3rd, activists including ACT UP COSTAS, Terry McGovern, members of Life Force, and women living with HIV went back to Atlanta to protest at the CDC. By this time advocates had recruited many HIV-positive women to join the movement. They were among hundreds of women attending the protest. On Saturday, December 1st, SisterLove Women's AIDS Project, which was based in Atlanta, hosted a Community AIDS Resource and Education Fair at Morehouse College, a historically Black college. In keeping with the tradition of ACT UP actions, that night there was a party for the advocates and activists participating in the protest. On December 2nd, advocates gathered to prepare posters for the protest. On December 3rd at 11 AM they gathered to go to the CDC.[44]

The demonstrators' demands were clear: altering the AIDS surveillance definition to include chronic pelvic inflammatory disease, chronic refractory vaginal candidiasis, and cervical cancer. They also wanted the CDC to augment the definition to ensure that anyone with a CD4 count under 200 be counted as having AIDS. They demanded that the CDC improve its data collection process on the causes of deaths of people with HIV, and establish a mechanism for regular reviews and revision of its surveillance definition. Importantly, ACT UP demanded that members of affected communities be included in the process of review and revision.[45] As the protest received national attention, the pressure on the CDC mounted.

THE FIRST BOOK AND CONFERENCE ON WOMEN AND AIDS

Given the lack of information about women and AIDS, ACT UP and the ACT UP New York Women and AIDS Book Group decided to take matters into their own hands by publishing their own book: *Women, AIDS, and Activism*. Released in 1990, the book was the product of an ACT UP Women's Caucus teach-in conducted at the Lesbian and Gay Community Services Center in New York City in March 1989.[46] The book pulled together what little information was known about women and AIDS at the time and sought to stake a place for women and AIDS in the national conversation about the epidemic. The book lays out the ideological foundations for ACT UP and laid the groundwork for what would become the dominant narrative about women and AIDS: that patriarchy and sexism were the cause of women's infections and the neglect of women in the AIDS response.[47] A chapter titled "Sexism and Women's Position in the AIDS Crisis," by Kim Christensen, provides text that animates the overall project:

> Sexist attitudes have had an enormous impact on the treatment of women in the AIDS crisis in the medical profession, public policy officials, and even some AIDS activists. Even more than sexism – a set of

> bigoted attitudes about gender – has been the institution of patriarchy which perpetuates male control of women's labor time, sexuality, and reproductive capacities. This male-control may be exercised by an individual man, as in the case of a battering husband, or by a male dominated institution, such as the Supreme Court, Congress, the New York Stock Exchange, the governing bodies of any of the major religions, or the medical profession.
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> Violence against women, including the legal/societal toleration of this violence, is one of the most blatant aspects of patriarchal oppression.[48]

There was also mention of the role of race in AIDS-related inequalities.[49] At several points in the volume, authors raise the difference in infection rates between women of color and white women.[50] Women of color authored chapters documenting their own experiences in the epidemic.

While social factors played an important role, several chapters raised the biological dimensions of women and AIDS. This was central to the newly established narrative about women and AIDS given the deep belief that female bodies were intrinsically different from male bodies. Some of this difference was attributed to organ-specific disease (pelvic inflammatory disease), some due to pregnancy and reproductive organs (gynecological cancers), and some to unique manifestations of STIs in women.[51] In the context of HIV, feminists had also begun to speculate that many of the issues that impacted women's vulnerability to other STIs might also increase women's risk of contracting HIV.[52]

The book was reviewed in feminist publications, including *On Our Backs* and *Sojourner: The Women's Forum*, and that helped carry the book from the health activism space to the larger feminist community.[53] The dialogue it engendered picked up on the growing concern about sexual violence in the larger feminist movement. The reviewer in *On Our Backs*, for example, took issue with the assertion in *Women, AIDS, and Activism* that sex offenders should be able to voluntarily and not mandatorily test for HIV. "What ramifications does this statement hold for women, who are disproportionately the victims of male sex offenders," she asked.[54] The review in *Sojourner* connected the issue to reproductive rights, highlighting data that suggested that clinics were turning away women living with HIV who wanted abortions.[55] Papers produced for the LGBT community, including the *Village Voice*, also covered the release of the book. Acknowledging that the editors of the book were primarily white, mostly lesbian women – a contradiction when it came to who was contracting HIV – the review praised the editors for expanding the contributions to include nonACT UP members, which broadened the voices and highlighted the plight of lesbians in the AIDS struggle alongside the destructive role of gender.[56]

AIDS activists also carried the ideas from their book into the first conference on Women and HIV/AIDS. The event took place at the Sheraton Hotel in Washington, DC.[57] Fifteen hundred people were in attendance for panels spanning a range of issues impacting women in the epidemic.[58] The conference included representatives from the National Institute of Allergy and Infectious Diseases (NIAID), and several subgroups from the NIH, including the Office of Research on Women's Health, the National Institute of Child Health and Human Development, and the National Center for Nursing Research.[59] A range of government agencies cosponsored the event including the Office of the Surgeon General, the Office of Minority Health, the National AIDS Program Office, the Alcohol, Drug Abuse and Mental Health Administration, the Food and Drug Administration, and the Health Resources and Services Administration.

Although the meeting was a demand of women's organizations, advocates felt that they were largely excluded from the planning.[60] Linda Meredith, a leader of the ACT UP Women's Caucus in DC, who had been appointed to the Steering Committee for the National Conference, resigned citing exclusion from the planning process as well as the appointment of a staff person who was not using inclusive planning methods for the conference.[61] Despite her resignation she spoke on a panel entitled Status of Women's Research.[62]

Their outrage at being excluded from the planning of a conference their advocacy helped create primed the advocates to protest. Their high-profile targets were Anthony Fauci, Director of NIAID, who had promised inclusion of women's rights advocates when communicating with Linda Meredith, and James Curran, the head of the CDC task force on AIDS. In the campaign to change the CDC definition of AIDS, Curran was an important figure. Part of his mandate was to define the disease itself. He had already been targeted by advocates. In one action, ACT UP members sent 20,000 postcards to his home. On them was a picture of his face with a target on it. While his family was upset by the barrage of postcards, Curran was unfazed. He felt that he was the target due to his position at the CDC and not due to his personal work, which had been long dedicated to issues regarding women's health. He hung the postcard on his wall at the CDC, next to awards he had received from the LGBT community, to remind himself of the range of reactions emerging from the demanding work of responding to the epidemic. Together, the flyer and award were a sign of the difficult work.[63]

During Curran's talk at the conference, he argued that the CDC definition could not be expanded because of the lack of an evidence base. He was interrupted by ACT UP Women's Caucus members who hung a banner and gave out leaflets criticizing the slow response to the issue of women and AIDS. Dr. Fauci also spoke at the conference, presenting general information about the epidemic. During the question-and-answer session he was challenged by women in Life Force, who pointed out that they already knew all he'd explained about the broad dimensions of the epidemic – they wanted specific information about women. When Daniel Hoth, head of the NIH Division on HIV, tried to speak, twenty-five HIV-positive women stopped him midway and read a statement together articulating three specific demands: change the CDC definition, give women disability benefits, let women into clinical trials.[64]

Alongside pressuring senior government officials, advocates used the opportunity to organize. They distributed copies of the *Treatment and Research Agenda for Women with HIV Infection*. It was a photocopied and bound manuscript describing the many issues related to women and AIDS.[65] The book was a call for research and action on the issue of women and HIV, and characterized women as the "most misdiagnosed, underdiagnosed, and underserved" population in the AIDS epidemic.[66] It detailed the variety of conditions that women with AIDS tend to get, echoing the demands for more attention to pelvic inflammatory disease, cervical cancer, and Human Papilloma Virus (HPV).[67]

The conference produced recommendations on women and AIDS that were to be distributed to Public Health Service agencies. While the recommendations were wide-ranging, they all advocated increased attention to women and AIDS: for an exploration of how HIV manifests in women, for more studies about HIV transmission and the existence of co-infections and cofactors of transmission, for a study of precancerous reproductive organ and genital tract lesions among HIV-infected women, and for investigation into the psychosocial needs of HIV-positive women.[68] The call for greater understanding of the biological workings of AIDS came with calls for specific modes of preventative care, including the need for gender-specific (gynecological) evaluations.[69]

1991–1992: THE TIDE BEGINS TO TURN

The conference, litigation, and advocacy were creating a stir and government officials were aware of it.[70] The national conversation on women and AIDS was also beginning to shift. Mainstream papers reconsidered the epidemic amongst women: In 1991, a *New York Times* headline read that "80,000 Women May Carry HIV." In 1992, *Time* magazine ran a story "Losing the Battle, Highlighting the Shifting Epidemic to Women," and *The Atlantic* magazine wrote that heterosexuals with AIDS were the second epidemic. The coverage had impact: The federal judge overseeing *S.P. v. Sullivan* read a *New York Times* article about a demonstration on women and AIDS. Despite the government's best efforts, she refused to dismiss the case.[71]

With the litigation ongoing, AIDS activists continued to carry feminist ideas forward. A key event came in 1991 when Democratic Representative Robert Matsui of California introduced H.R. 2299, calling for an AIDS Disability Advisory Panel to assist Congress and the secretary of health and human services to more effectively meet the needs of people living with HIV. The panel was to consider the special concerns of women, among other populations, and comprise nine members, including at least one person who was living with HIV. Reflecting feminist demands, the panel was tasked with considering the specific course of HIV infection amongst women and "the symptomatic manifestation of HIV infection in women as it differs from men."[72] The bill listed interim standards for impairments that would result in a person being deemed disabled; they included cervical dysplasia and cancer, chronic vaginal candidiasis, and pelvic inflammatory disease that was unresponsive to standard medical therapy.

These gynecological illnesses reflected the feminist demand that women-specific identifiers be included in the determination of AIDS-related disability. In driving this point home, Republican Congresswoman Constance Morella, a cosponsor of H.R. 2299, stated that she was "deeply concerned" by the SSA's use of a CDC definition that "continues to rely mainly on AIDS-indicator conditions in men."[73] In January of 1991, she wrote to Linda Meredith that she planned to cosponsor Matsui's bill,[74] indicating that her support for the bill may have partly been in response to advocacy by the ACT UP Women's Caucus.

Under pressure in June 1991, the SSA released revised regulations acknowledging that challenges had arisen in its use of the CDC definition to provide SSI and SSDI. Although the new regulations acknowledged that women and men experienced HIV differently, they did not meet the demands of activists and women living with HIV who called for a determination of disability based on identified illnesses specific to women. Instead, the new draft regulations of the SSA still required a determination of functional impairment, even if gynecological conditions associated with AIDS were present.[75] In response, and as evidence of the high-profile nature of the debate, over 3,000 comments were received by the SSA. The feminists of ACT UP critiqued the AIDS definition for not going far enough. Terry McGovern also sent a letter to Lorraine Novinski at the Department of Justice. The letter requested that a series of illnesses be added to the list, including chronic pelvic inflammatory disease, chronic anemia, recurrent herpes, and chronic genital ulcers.[76]

In April 1992, as the litigation was ongoing and the new SSA rule was still under consideration, the Subcommittee on Social Security and the Subcommittee on Human Resources held a hearing to identify the obstacles faced by women, children, and individuals with HIV-related disabilities from qualifying for SSI and SSDI. The official rationale of the hearing echoed feminist ideas about why women had not been detected with having HIV and had been denied benefits: "SSA's medical criteria for HIV-related disabilities are based largely on studies of adult males, they exclude many symptoms experienced by women and children." The feminist influence in the context of AIDS was on display as ideas of biological differences in the manifestation of HIV and AIDS appeared in testimonies by politicians, medical experts, and activists alike.

Testimony from lawyers representing AIDS clients criticized the SSA for slow assessments of disability and failure to be responsive to the needs of women. In her testimony, in which she described her increasingly worsening health, Phyllis Sharpe, a beneficiary of social security, mobilized ideas of inclusion and difference to argue that the SSA was failing to address the needs of women: "The old definition was bad enough. All the medical conditions which were listed were from studies of gay white men. How does that apply to me? I have a different body chemistry than a gay white man. Now the new definition has problems."[77] Sharpe and other advocates had support from leading medical organizations, including the American Medical Association (AMA), the American Academy of Pediatrics, and the Physicians Association for AIDS Care (PAAC). Each of these institutions carried the weight of an association of physician-experts whose primary allegiance was to scientific evidence rather than politics. Yet their testimonies read as similar to those of feminists, and often appealed not to science but to the morality of not addressing the issue of women and AIDS. Each organization argued that its primary constituents would benefit from a broadening of the SSA definition by allowing a greater number of individuals to receive benefits. The AMA and PAAC made strong statements in favor of expanding the AIDS-defining illnesses list.[78] Referencing the litigation before the courts, the AMA statement made clear that the SSA needed to better respond to people living with HIV, highlighting the fact that the challenges of qualifying for disability benefits are "compounded for women, children, and others who are not typical of the earliest and most thoroughly studied individuals infected with HIV."[79] The PAAC made a passionate appeal:

> HIV disease is a disease of the disenfranchised of our society. It is a disease of the medically indigent, of the poor, of the homeless, of gays, of injection drug users, of people of color and of women – groups who at best have been relegated to some secondary status as citizens, and at worst have been targets of discrimination and sexism.
>
> Women may have suffered disproportionate [sic] from this epidemic than other groups. First, they have suffered because their initial symptoms of HIV disease often have not been diagnosed due in part to the perception by many physicians that HIV disease is a disease of gays and injection drug users. Over and over, from every major city in this country I have met women who have told me horror stories of the failure of their physician to diagnose their HIV disease … Next, when women are finally diagnosed with HIV, many of these women are unable to find a physician who can diagnose and appropriately treat the many manifestations of this disease unique to women. Many of these unique manifestations are gynecological disorders – conditions with which many primary care physicians and many HIV specialists are unfamiliar. However, gynecologists are generally not familiar with HIV disease, which leaves women in a classic Catch 22.[80]

Despite the testimony of physicians at the hearing, the SSA resisted the passage of H.R. 2299, stating that its current guidelines for determining disability relied on "documented scientific information" and that this was foundational to the crafting of SSA regulations.[81] In doing so, it pushed back with another powerful frame: the objectivity and neutrality of science.[82] Building from this counterframe it argued that it could not and should not take guidance on how to define an

AIDS-defining illness from legislators or other nonscientists. The SSA argued that it was working with the NIH to ensure that the newest medical listings for determinations of disability included issues facing women to ensure science-based regulations on AIDS.[83]

By this point in time, the SSA was under pressure to do better. The hearings were overwhelmingly critical of the SSA's resistance to being more inclusive of women with HIV in its disability determinations. To drive home the general dissatisfaction with the SSA, Senator Thomas Downy quoted the MFY Legal Services and HIV Law Project brief before the court in *S.P. v. Sullivan*:

> We filed the lawsuit because our clients experienced terrible delays and were subject to incredible hardship in their attempts to qualify for benefits. We watched clients die before they ever qualified. We watched them grow sicker and sicker while we fought a system which recognized none of their impairments as severe and disabling HIV-related disease and almost every single plaintiff in the lawsuit was eventually found disabled at their application date, 1, 2, 3, or 5 years before they actually won benefits.[84]

In response to this criticism, the SSA implied that it would revisit its proposed rule, which would now benefit from the several thousand comments it had received. In keeping with its emphasis on an expert-driven process, it argued that in considering the comments its rule would reflect the experience of physicians and service providers to improve the experience of filing for disability benefits. By this time, the CDC had repeatedly communicated to the SSA that the SSA should not use the CDC case definition to assess disability.[85] Yet, the SSA continued to do so.

Although the CDC definition was not the central focus of the hearings, because the SSA relied on the CDC definition to make its disability determinations in the context of HIV, the CDC definition was also being called into question.[86] The CDC felt bound: It wanted a careful list of symptomatic illnesses that were an accurate representation of the virus. This produced pressure to ensure that illnesses not associated with HIV were not on the symptomatic list used for diagnosis. The CDC also felt that it had a more effective strategy in the pipeline; with the increasing use of blood tests it could utilize CD4 counts to determine if a person has AIDS. The CDC landed on 200 cells/ul as a cutoff. In other words, having a CD4 count below 200 cells/ul would result in a diagnosis of AIDS. The idea was that 200 cells/ul would capture many people living with HIV but still be slightly above a CD4 count that would necessarily render someone ill.[87] From Curran's perspective the 200 cells/ul was an inclusive definition because it would allow for an AIDS diagnosis for many people who were not yet experiencing the symptoms of AIDS.

Congress had also begun to seek answers to the question of the AIDS definition. In 1992, the Subcommittee on Human Resources and Intergovernmental Relations for the House Committee on Government Operations, the Office of Technology Assessment (OTA) issued a report exploring the implications of the alterations in the AIDS case definitions. The report noted that the CDC was resisting any modifications to the AIDS case definition for three primary reasons. First, the CDC argued that doing so would increase the complexity of the definition and thus complicate state-level reporting of AIDS. Second, and related, the CDC did not want to add in any infections or cancers that did not have an already established relationship to HIV; the list as it existed only had infections and cancers that appeared in immunocompromised individuals. The CDC argued that broadening that could result in an artificial inflation of the AIDS count. Finally, the CDC preferred to rely on CD4 counts rather than the existence of nonopportunistic illnesses in making determinations on the progression of HIV to AIDS.[88] This decision would allow the CDC to determine AIDS status through a number rather than through illnesses like pelvic inflammatory disease. This appealed to epidemiologists who felt a numerical measure would allow for a standardized approach rather than one reliant on diseases not always associated with immunocompromised individuals. The CDC predicted that the expansion of the AIDS case definition would result in a 52 percent increase in the total number of living AIDS cases in the United States, with an increase in reporting amongst women. According to the OTA, the federal agency responsible for advising Congress on scientific and technological issues, states reported that with a change in case definition to include gynecological health issues the number of AIDS cases would increase between 36 percent and 135 percent. In turn, there would be financial costs: The more people diagnosed with HIV and AIDS the greater the burden on state and local governments to provide services.[89]

In the face of ongoing resistance from the CDC, a coalition of organizations, including the HIV Law Project, ACT UP, New Jersey Women AIDS Network, and the American Civil Liberties Union (ACLU), developed a proposal that demanded the addition of gynecological conditions including invasive cervical cancer and pelvic inflammatory disease. The proposal had over 300 signatories including individuals and organizations.[90] It was delivered to CDC officials in June of 1992 at the International AIDS Conference. Activists also engaged in a carefully planned national campaign. They arrived at the CDC in Atlanta and at the Health and Human Services Agency in Washington, DC carrying signs that read "The CDC Definition Is Sexist, They Are Killing Women" and "Women and AIDS: Dead but Not Disabled!" Key leaders in the AIDS response, including Fauci, were targeted by activists at conferences. In Atlanta, feminists were arrested at the CDC demanding that women be included in the AIDS definition. They encouraged people on the ACT UP list to call senators and demand the inclusion of women-specific illnesses in the AIDS definition and question the CDC's lack of commitment to women. As described by activist, Maxine Wolfe:

> They [the CDC] were so afraid of us by that time. We had done all these demonstrations. We had gotten groups that were so diverse, to support this campaign, from all over the country. We showed that we could get Congress people who would start to investigate the CDC. We used every single tactic that you could possibly use. It was really like community organizing and political organizing at its best. It went from the grass roots up, and we had this committed group of people. We would send out a letter and say, write a letter to your Congressman, and all these people would do it, because they wanted to change it.[91]

With discussions ongoing, the CDC decided it would move to a definition of AIDS that emphasized CD4 counts and defined AIDS as anyone with a CD4 count under 200. Some segments of ACT UP agreed with this strategy and felt that 200 cells/ul represented a good compromise. This solved part of the problem in that the new AIDS case definition would be inclusive by default. Feminists considered the consequences of this. On one hand, the new definition would allow more women to be detected with HIV and AIDS. On the other hand, it did not get to the core concern that female-specific manifestations of AIDS would be left off of the list of illnesses. At the urging of physicians in their movement, feminist activists felt that they should push ahead with naming gynecological conditions, with one important modification. McGovern was concerned that they would only be able to move forward for symptomatic conditions that had a robust evidence base, given the CDC's emphasis on evidence-driven guidelines. Feminists knew they would have to modify their claims to fit the CDC's perception of itself as a value-neutral institution. From this perspective, cervical cancer was the only gynecological condition that had an evidence base.[92] So activists narrowed their broader set of symptomatic illnesses to the more limited demand that invasive cervical cancer be included in the list of AIDS-defining illnesses.

In September 1992, the CDC held an open meeting about the transformation of the definition of AIDS. An official transcript of the meeting reveals that the CDC had begun to warm to the idea of broadening the definition of AIDS, and that epidemiologists had begun to question the reliability of the CDC's data. This created yet another opening for feminists to demand that gynecological issues be included in the CDC definition. These shifts meant that the CDC had to rethink its boundary between science and advocacy. That was evident in the opening remarks by CDC representative James Curran, who acknowledged that the AIDS surveillance definition should be revised soon because of the "serious morbidity due to HIV infection that is undercounted." "Many people," he acknowledged, "are hospitalized and some die with HIV infection without being counted as a case of AIDS."[93] Importantly, Curran stated that while the CDC did not address healthcare and social services for people living with HIV, it clarified the ongoing need for services. For Curran, the "AIDS surveillance has served and will continue to serve as the conscience of the HIV epidemic in our country." The statement appears to be a clear reference to the denial of benefits from the SSA – with the CDC acknowledging that whether or not it sought to have this role, it would hold the key to understanding and responding to the epidemic.[94] The expanded definition sat in the most "simple, direct, and objective" way to assess advanced immunosuppression: CD4 counts.[95]

Supporters of the expansion of the AIDS-defining illness list spoke at the meeting. Marion Banzhaf of the New Jersey Health Department presented a consensus statement signed by over 250 organizations calling for an expansion of the AIDS definition, and demanding that the surveillance definition include cervical cancer, cervical dysplasia, pulmonary tuberculosis, and recurrent bacterial pneumonia.[96] Women's advocates also pushed against the use of CD4 tests as the exclusive way to determine HIV or AIDS status because the request for a CD4 test normally only occurs because of the assumption that a person has HIV. This would continue to leave women with HIV without a diagnosis.[97] Terry McGovern drove home the point in emphasizing that CD4 counts alone are not enough to determine whether a person had progressed to AIDS, arguing that many gay men with Kaposi's sarcoma or pneumocystis pneumonia had CD4 counts above 300 or 250 respectively.[98] Women living with HIV also spoke, advocating that invasive cervical cancer, chronic vaginal yeast infections, and pelvic inflammatory disease be added to the list of symptomatic illnesses which could trigger an AIDS diagnosis.[99] They argued that the evidence base had changed – mandating a new definition of AIDS for the 1990s. They demanded to be recognized, and as one activist remarked:

> I leave you these words so that every time you hear my voice or see my face you'll know I'm holding you accountable and responsible for the unnecessary suffering of women the world over. Because I will not distort my voice! I will not cover my face! And I certainly will not live the remainder of my life hiding in the shadows! My name is Wendy Alexis Modeste and I'm a proud African-American woman who, despite the CDC, is living with AIDS in Syracuse, New York![100]

Despite strong advocacy for expanding the definition, many participants argued against adding illnesses.[101] From their perspective, the CD4 count of 200 represented the most objective and consistent way to determine whether someone's HIV infection had progressed to AIDS. Despite the differences in position on the expansion of the CDC definition (between those supporting only the shift to 200 CD4 count and those who wanted the inclusion of symptomatic illnesses) speakers tended to agree that people of color and poor individuals would not receive the CD4 count blood tests due to an inability to pay for them. In a panel on cervical cancer, tensions about whether or not to include invasive cervical cancer reemerged. Advocates called for the inclusion of invasive cervical cancer and epidemiologists presented growing evidence that women with HIV do experience forms of cervical cancer that rapidly progress. Yet, despite this, one epidemiologist concluded: "I'm going to look at this only from the epidemiological point of view. I think disability should be awarded on the basis of disability and that the rationing of health care in the U.S. by income is inexcusable, but the definition is not the way to change that."[102]

Although the speaker was not from the CDC, the position reflected the concerns that epidemiological and scientific surveillance should remain distinct from the distributional implications of the AIDS definition. Other medical experts leaned into broadening the definition, evidenced by the statement from a professor at the University of Puerto Rico School of Medicine who "hoped to see an inclusion of premalignant cervical conditions as well as advanced cervical cancer in the AIDS case definition" because that "would improve the chances of such women and will give a better perspective of the condition as it relates to women."[103] Similarly, a representative of the American College of Obstetrics and Gynecology emphasized the need to integrate gynecological care into the AIDS response because gynecologists were not tuned into the AIDS epidemic and cases were being missed. Inclusion of invasive cervical cancer would bring the field of gynecology directly into the diagnosis of AIDS.[104]

Numerous ACT UP members from cities around the country (including New York, DC, and Los Angeles) joined other activists and members of Life Force in continuing to pressure those resisting the inclusion of cervical cancer during conference discussion periods.[105] Advocates were frustrated with what they saw as a blatant double standard: the obvious denial of the inclusion of women's issues, while symptomatic illnesses associated with men were included from the beginning of the epidemic, despite little evidence of the connection to HIV. One after another, they stepped up.

Linda Meredith, representing ACT UP, argued that although the CDC was not responsible for helping people access healthcare, it was in fact responsible for tracking the epidemic accurately.[106] The National Minority AIDS Council representative Anita Taylor told the group that the expansion of the definition to include gynecological conditions would sensitize health practitioners to the possibility of HIV infection in women and help with early diagnosis and treatment of women.[107] Getting the definition right in order to help people access Medicaid and social security benefits was especially necessary for indigent people and people of color living with undiagnosed HIV, she said.[108] And journalist Susan Shaw, from the People With AIDS Coalition, argued that understanding the relationship between science and politics was crucial to formulating an equitable AIDS response: "We would like science to be apolitical," she said. "But the fact is science is political, and people with AIDS are trying to use it to their best interests."[109]

Their interventions seemed to strike a chord. During the question-and-answer period, epidemiologists and physicians began to reveal their own ambivalence about the accuracy of epidemiology. In striking terms, one epidemiologist noted the shortcomings of the field:

> [E]pidemiology is not a pure science. Epidemiology is a fairly clean science. But we never have the luxury of being an absolutely pure science,

> and there are always compromises both in specificity and sensitivity that we have to make [in] our case definition. So we don't hold ourselves out as being in any way even nearly an ivory-tower type of science.[110]

The idea that there was an attainable, pure science by which to understand the AIDS epidemic – and that epidemiology did not meet that standard – produced an opening for legitimate activist claims that in fact the evidence that had been driving the CDC definition thus far was incomplete.

James Curran's comments at the end of the meeting reflected the transformation underway at the CDC. The goal of the meeting was to understand how to expand the definition, he said. He acknowledged that HIV creates unique issues due to the underlying discrimination faced by people living with HIV, which is compounded by fear in the epidemic: "Health care workers are afraid. People in schools are afraid. Other people are afraid. And that's on top of racism, sexism, and something that we didn't hear much about today, and that's homophobia,"[111] he said. He also offered up a practical reason for settling on the number 200 as *the* number for using a blood cell count to determine if someone had AIDS:

> So why did we pick less than 200 CD4 cells? The reason we picked less than 200 CD4 cells as one approach to expanding the AIDs surveillance definition is that every doctor that does any good and knows how to take care of an HIV-infected patient does approximate CD4 counts. And the CD4 count is one measure that is based upon the adequacy of medical care. And, in general, people who have less than 200 CD4 counts need a lot more intensive preventive medical care and curative medical care … so we want to reflect what we think is the ideal medical care.[112]

For Curran, adding the CD4 count cutoff also mattered because it would further incentivize doing the CD4 tests to begin with. He described how public health officials sought out diagnoses of HIV so that they could approach the legislature to demand increased funding for HIV. Curran also suggested there was a structural issue with the diagnosis of HIV through gynecological conditions – that many internal medicine physicians did not feel comfortable conducting pelvic exams. To him, this was "crazy." Adding gynecological conditions, like cervical cancer, to the case definition would send "an important message to doctors, to women, as well as to society … that gynecological problems are an important part of the spectrum of disease in women, and that getting pap smears because of concerns about cervical cancer is an important concern and issue."[113] Curran's position reflected a shift away from maintaining a narrow definition of AIDS that would exclude cases from being detected and toward a broader definition of AIDS that would ensure delivery of care and better surveillance.

FEMINIST VICTORY

In December 1992, the CDC issued revised guidelines inclusive of invasive cervical cancer.[114] Advocates credit their own activism for the shifting definition. And, even while the OTA acknowledged that it was lawyers who brought the issue of invasive cervical cancer to its attention as an AIDS-defining illness,[115] the CDC credited the change to new data in the way HIV manifests in women.[116] By positioning the change as one based on evidence, the CDC was able to sustain its image as an institution driven by scientific evidence and resistant to politics.

A few days before the official release of the CDC's announcement, McGovern went to the bedside of Katrina Haslip to share the good news. Haslip whispered a statement to McGovern, her eyes closed in exhaustion. The statement was read out loud at a press conference held by advocates:

> I don't want for one moment, the CDC or the FDA or any of our state and city entities to smile today and act like they have done me a grave justice. In fact, it was activists like the women's caucus of ACT UP, Black AIDS Mobilization, and community based organizations that are grass roots and peer-oriented that pressed the CDC into changing this definition.
>
> They probably still don't think our vaginas are important or women's healthcare is important. This is their form of pacifying us and trying to silence us. I do not want them to come smiling today or tomorrow at a press conference like they have discovered something new or that they have added these conditions because there is new statistical data.
>
> Women's health groups like the Women's Prisoner's Association, the Division of Substance Abuse, the Borough President's Offices, Women and AIDS group and community based organizations like Manhattan Task Force on AIDs have lost blood, sweat and tears, have suffered pain, aches, frustrations, lost loved ones and they themselves have died [and] while we waited and watched the CDC did nothing.

> So, okay, you gave us a few things but we will not carry on a farce. We will not be silent. We will continue to scream and advocate for ourselves on women's health issues and CDC you will stop killing women by the omission of certain gynecological illnesses and you will learn to record data about women and study and research the natural history of this disease in our bodies. Shame on you CDC, we will never be silent again.

The news of the definitional change received national attention. And despite her immense frustration, in a story about women and AIDS in the *New York Times*, Haslip declared victory:

> I am, and have been, a woman with AIDS, despite the C.D.C. not wishing to count me. We have compelled them to.[117]

Soon after, at the age of thirty-three, Haslip died. The guidelines went into effect one month later.[118] Hers was not counted as an AIDS death.[119] Her framed photo sits on McGovern's desk still today.

Following the shift in the CDC definition, and in consultation with experts, lawyers, and people living with HIV, the SSA revised its rule in 1993. The SSA, however, went even further than the CDC, including both invasive cervical cancer and pelvic inflammatory disease on the listing of illnesses that, when paired with an HIV diagnosis, would allow for a greater possibility of receiving benefits. Taking on the feminist position, the agency acknowledged that "HIV infection manifests differently in women than in men."

This was a feminist victory. Now embedded in the scientific institutions that defined AIDS – and in regulations that managed the flow of resources – was a feminist idea that would fundamentally alter the response to the epidemic.

In September 1994, the World Health Organization (WHO), in its *Weekly Epidemiological Record* – a publication that serves as a means for rapid dissemination of information on disease outbreaks and progression – updated its definition of AIDS.[120] In keeping with the shift in the CDC definition, the WHO also added invasive cervical cancer to its case definition for AIDS surveillance, which meant a positive HIV test coupled with one of a list of illnesses would result in a diagnosis of AIDS. The expanded list of illnesses reflected feminist demands: Invasive cervical cancer was now included.[121]

The change in the surveillance definition meant that more women living with HIV around the world were counted among those infected by the virus or having a diagnosis of AIDS.

The onslaught of diagnoses among women would transform the face of AIDS. Acknowledging the uptick in heterosexual transmission and the fast-growing number of women suffering from AIDS, the United Nations (UN) agencies declared that the global epidemic had feminized.

Women and girls were now one of the fastest-growing groups contracting HIV. But a question still remained on the table: How should experts explain the fast-growing epidemic among women? As Chapter 4 reveals, feminists had an answer.