

Rethinking the “Straight State”: Welfare Politics, Health Care, and Public Policy in the Shadow of AIDS

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Abstract

This article considers together questions of political economy and sexual politics to establish how welfare bureaucrats, health care advocacy groups, and queer activists understood and debated health care policy at both the federal and state levels between the late 1970s and late 1980s. Much attention has been paid to political struggles for treatment of HIV and AIDS during the 1980s, but this article focuses on efforts of people with AIDS (PWAs) to access the labyrinthine and, up to that point, resolutely heteronormative welfare system. I argue that efforts of AIDS activists to access public health benefits through the welfare state highlighted the inadequacies of a system predicated upon the centrality of disability as a marker of eligibility for health benefits. As more and more of those suffering from medical conditions related to what we now know as HIV lost private health insurance, they were forced to seek classification by state social welfare agencies as medically disabled in order to access public funds. However, the state welfare apparatus did not work on the principle of medical need, but rather adopted the Center for Disease Control’s categorization of disability via disease categories that rendered those with more powerful advocacy voices more likely to gain the imprimatur of state approval. As the AIDS crisis developed and affected a diverse range of people by the end of the decade, it became clear that the Social Security Administration was unwilling to broaden access to the welfare system to cope with a diversifying epidemic, one that exemplified a wider reality of poverty and exclusion rather than a limited crisis affecting small numbers of primarily white males. I examine the dynamics of welfare politics via both grass roots activist efforts and bureaucratic

policymaking to show that the 1980s witnessed the transformation of the “straight state” into one that ended up privileging gay men over other claimants on a ramshackle and inadequate welfare system. Government agencies responded fitfully to activist pressure, but they also moved to restrict access to the welfare state to ensure that a rapidly diversifying epidemic would not break the limited and punitive boundaries of US social policy.

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In 1975, the Society of Individual Rights, a San Francisco gay rights organization that had been a leading part of the campaign for equal rights since the mid-Sixties, published a “survival manual” under the auspices of its magazine, *Vector*. Announcing the city as “the Mecca of nearly every form of lifestyle you would ever want to encounter,” the manual provided information for the newly-arrived gay resident on “housing, food, clothing, legal, medical and dental referrals....We even tell you how to get on General Assistance.” Readers could view information on helplines, social services, and gay-friendly businesses. A whole section on “medical aid” detailed hospitals, health centers, and clinics, including St Mary’s Hospital Clinic whose “fees on sliding scale, will help you get on Medi-Cal,” and the City VD Clinic, described as a walk-in facility with “no age or residency requirements.” A section on “welfare” detailed how General Assistance and Supplementary Security Income for the disabled (SSI) worked and gave information on how to apply for food stamps.¹

It was no coincidence that a manual devoted to showcasing the opportunities furnished by gay liberation would also advertise routes into the nation’s ramshackle welfare system. The emergence of gay men and women from the closet in these years was about more than sexual “liberation,” an ongoing process of community formation to free queer Americans from the shackles of heteronormativity. Those who came out had health care needs, whether they be access to sexual health clinics, women’s clinics, or private health coverage protected in an increasing number of jurisdictions by anti-discrimination laws. When a Philadelphia doctor wrote in the mid-1970s that the “gay health movement is coming out of the closet,” he was referring to national gay health advocacy as an addition to the plethora of interests in the wake of the rights revolution pushing for greater access to health

care services.² By the end of the decade, organizations such as the Bay Area Physicians for Human Rights were offering a range of health services for gay people, and in 1978 the National Gay Health Coalition held the first national gay health conference.³ When the American Psychiatric Association declared in 1973 that “homosexuality per se does not constitute any form of mental disorder,” the legitimization conferred opened up the possibility for the sexually non-normative to access the benefits of social citizenship until then restricted by what historian Margot Canaday has termed “the Straight State.”⁴

The fact that queer Americans would require access to the nation’s complex and inadequate social safety net became abundantly clear when in the 1980s gay men started to become afflicted by a range of crippling chronic illnesses related to autoimmune deficiency. A doctor at the National Cancer Institute reported in mid-1982 that, of 300 identified cases, “290 were men and 242 of the 290 were homosexual or bisexual... Once the syndrome has become chronically manifest, the various components have been hard to treat, and it is predicted that an ultimate mortality rate of 70-80 percent may be found.”⁵ A year later, as the death toll from what would become known as Auto-Immune Deficiency Syndrome (AIDS) rose inexorably, the Social Security Administration recognized AIDS as a disability, a visible marker of physical impairment mainly at that point affecting previously able-bodied men that made them unable to work and likely to end in death.⁶ This early association on the part of welfare agencies of disability through immune deficiency with gay men, and their reluctance to expand that definition as the HIV epidemic spread, serves as an important case study of the peculiar dynamics of welfare politics in the “age of Reagan.” That the SSA was so quick to include some gay men in the Supplementary Security Income program, also making them eligible for Medicaid, demonstrates the gradual erosion of the “straight state” at a time of supposed conservative political ascendancy. At the same time, however, the intractable opposition faced by others with HIV infection trying to access welfare benefits later in the

epidemic exemplifies the processes by which policymakers and bureaucrats aimed to prevent the US welfare system from becoming a wide-ranging social safety net predicated upon poverty. In giving their official imprimatur only to certain HIV-related illnesses as being markers of disability, the SSA created a hierarchy of entitlement that privileged those able to shape the policy discourse on AIDS at the start of the epidemic, thanks to their vocal activist network and ready access to the federal bureaucracy. As the epidemic widened during the 1980s, its central markers became poverty and social exclusion at a time when federal welfare bureaucrats were determined to place ever greater limits on access to the welfare state. Grassroots activism diversified to encompass an ever-growing crisis but faced a Social Security Administration unwilling to respond when to do so was to acquiesce in a potentially significant expansion of the welfare rolls beyond those easily perceived as “disabled.” The SSA’s hostile treatment of multiple epidemics tells us much about the ways in which broader political hostility to public assistance programs embedded racial and gender discrimination in social welfare policy in these years. The extension of welfare benefits to People with AIDS forms part of a larger story of the relationship within social policy in the United States between notions of the “deserving” and a welfare state unable to countenance universal access as its core guiding aim.

Historians and social scientists have long understood the contingent forces acting to limit the development of a robust social safety net in the United States over the last century. Some of these forces can be traced to the political and structural dynamics of American governance. The federal structure of the US, the origins of American social welfare in categorical programs directed to particular categories of the “deserving”, and the power of private sector interests in directing and limiting benefits programs are cases in point.⁷ Other scholars have pointed to the racial and gendered ideological underpinnings of the social welfare system, in which broader processes of discrimination have found expression.⁸

Canaday added a new dimension to these ways of framing the history of welfare by showing how the American state privileged heteronormativity and stigmatized and policed sexual dissidents. Her ground-breaking study concluded in the 1970s, when significant LGBT activist strategies were still in their infancy, leaving the crucial period of the extension of welfare benefits – public and private - to some queer Americans in the 1980s unexplored.⁹ While there is a rich scholarship on AIDS activism in the 1980s from a variety of perspectives, discussions of its interaction with the state are limited beyond understanding efforts to gain access to drug treatments and research, or charting the divisions and problems within the Reagan administration.¹⁰ Furthermore, historians of the US welfare system have tended to relegate the place of the AIDS crisis in debates over social policy to the background.¹¹ While the number of people with AIDS receiving SSI benefits in the mid-1980s numbered only in the tens of thousands, far fewer than those receiving Medicaid as recipients of the Aid to Families with Dependent Children program or as poor elderly Americans, the AIDS crisis is significant because it took welfare politics in a new, uncharted direction.¹² AIDS was not easily understood as a “disability” in the way amputation of limbs or black lung disease were, but it quickly became enmeshed in that system. As a California AIDS bureaucrat declared, AIDS “embraces not one but several traditional taboos. It is sexually transmitted, it involves the homosexual subculture and it is incurable. You add that to the fact that it is primarily spread out of the homosexual community to the IV drug abusers to the minority population and that’s strike five. It is an exceedingly difficult issue for public policy types to address.”¹³ That the initial patient population comprised previously “healthy” men, normally outside the boundaries of the welfare system, invites historians to explore what political scientist Cynthia Daniels has called “evidence of male weakness and vulnerability” in health politics in order to understand how gendered hierarchies in the welfare system of the 1980s informed who could access public funds and who could not.¹⁴

The implications of this battle to access health care for our understanding of the politics of sexuality are significant. The Reagan years witnessed a major shift in political conceptions of sexuality and of social citizenship, displacing that which had set the terms of both between roughly the 1870s and 1930s. It is widely understood that the decades spanning the end of the nineteenth and early twentieth centuries witnessed the medical and scientific construction of modern categories of sexuality.¹⁵ They also saw the emergence of the categorical social welfare system during and after the New Deal, a set of employment-based benefits for breadwinners and categorical state benefits for poor parents, widows, the needy elderly and veterans.¹⁶ At the same time as policymakers and lawmakers were constructing the modern heterosexual and its antithesis, they also built the nation's public and private social safety net around similar heteronormative tropes.¹⁷ This symbiotic relationship between the political categories of sexual beings established in the late nineteenth-century and the dynamics of social policy underwent, I argue, a substantive reorientation in the 1970s and 1980s. Homosexuality was not only undergoing a process of decriminalization and increasing acceptance by medical authorities.¹⁸ Sexual liberation acted as a catalyst for intense political lobbying for access to public services that served to destabilize established categories of the deserving and undeserving in federal welfare politics. In the early AIDS crisis it was gay men who demanded a place at the welfare table, men whose opportunistic illnesses allowed them to brand themselves as "disabled" and thus worthy of support as their access to the private health system diminished.¹⁹ Childless women and communities of color, by contrast, often found themselves without the political clout in public health politics afforded by a clear link to an epidemic associated with the image of the sick white man.²⁰ To bureaucrats classifying ill people as disabled, and thus eligible for benefits such as Medicaid, a young white male with Kaposi's Sarcoma was obviously infected with HIV; yet a woman

with cervical cancer, often a product of HIV infection in females, could not so easily demonstrate a self-evident causal link.

The subject of this article is the process by which federal bureaucracies categorized disease, afforded benefits to those with the most privileged advocacy organizing, and divided welfare recipients in ways that reflected deep class, racial, and gendered divisions in the US's public-private health care system.²¹ My central focus is a welfare program that actually grew during the Reagan era: Supplementary Security Income (SSI). A federal program created in the early 1970s out of the previously state-managed programs Aid to the Permanently and Totally Disabled and Old Age Assistance, this was the primary means by which people with AIDS could access the nation's health care system if they lacked or lost access to private health insurance. The program easily dwarfed the other possible route to health care for the disabled, Social Security Disability Insurance (SSDI), which required recipients to have spent years paying Social Security taxes in order to accrue benefits, and provided access to the Medicare program. Unlike the SSI and Medicaid systems, which provided immediate coverage once eligibility requirements had been met, SSDI benefits only kicked in five months after a diagnosis of disability, and at that point claimants would need to wait a further twenty-four months for Medicare coverage. Policymakers' determination to restrict their benefits to the permanently or long-term disabled resulted in timeframes for coverage that excluded all but a handful of AIDS patients in the 1980s, most of whom died before they could qualify.²²

The federalization of SSI in the Social Security amendments of 1972 became a crucial, if unexpected, development in the unfolding gendered and class politics of AIDS in the 1980s. By the late 1970s SSI, contrary to expectations, had become more of a disability benefit than one primarily targeting the needy elderly.²³ This program expanded during the 1980s despite the Reagan administration's abortive attempt to purge people from the rolls,

and the number of the disabled receiving SSI increased year on year by an average of about three percent.²⁴

As a consequence of these trends, access to Medicaid through a state appraisal of disability became a critically significant part of the story of health politics during the AIDS crisis. As most people with AIDS (PWAs) in the early years of the epidemic were men, and because definitions of disability were predicated upon categories of illness and disease, not the mere fact of being unwell and unable to work, it was inevitable that the early activist efforts to shape welfare policy would not speak to a wider epidemic and signalled the limited possibilities of an LGBT politics not firmly rooted in broader narratives of exclusion. This illuminates the paradox of a welfare bureaucracy expanding Medicaid eligibility at a time of supposed retrenchment, but through a mechanism that directed resource primarily to men, at least until AIDS activists recalibrated their political campaigns in the early 1990s to make the particular health needs of women part of their strategy. In essence, therefore, this study manifests how questions of power, respectability, and inclusion in the welfare state's definition of the needy citizen in the 1980s complicates our understanding of what happened to welfare liberalism in the Reagan era.

Queering Medicaid: disability politics and access to health care

“A new potentially lethal syndrome is being seen among otherwise healthy young gay males in New York and California,” reported the newsletter of the Bay Area Physicians for Human Rights in July 1981. “Kaposi’s sarcoma has been found to be associated in some patients with opportunistic infections such as pneumocystis carinii pneumonitis and (cryptococcal) meningitis....The pathogenesis of the syndrome is as yet unknown.”²⁵ The AIDS crisis initially seemed to affect primarily gay men, and early activist responses adopted the strategy of asserting the rights of those who seemingly only lacked access to full rights of

citizenship because of their sexuality. The well-known “Denver Principles” adopted at the Denver National Gay Health Conference in July 1983 proposed the term “People with AIDS” rather than “patients” or “victims” as a term of reference for those affected by the virus, rejecting “attempts to label us as ‘victims,’ a term which implies defeat, and we are only occasionally ‘patients,’ a term which implies passivity, helplessness, and dependence upon the care of others.”²⁶

For those at the epicentre of the AIDS epidemic in the 1980s, one central issue was that those suffering physical medical complications arising from this new, unknown syndrome were far from well, and needed access to the nation’s labyrinthine health care system. As the unfolding crisis led to increasing numbers of cases of employment discrimination against gay men and their families, and as deteriorating health of People with AIDS (PWAs) forced many out of active employment, access to the welfare state became a crucial avenue to covering health care costs through Medicaid, as well as providing some degree of income through the SSI program. Unfortunately, in order to access these programs applicants were required to negotiate a series of logistical barriers that would serve to exclude many of the most vulnerable, whose AIDS-related illnesses lay outside the narrative of disability constructed by the SSA in dialogue with an early AIDS activism dominated by middle class white men.

As AIDS began ravaging cities like New York and San Francisco in the early 1980s, the Social Security Administration made a decision in April 1983 that seemingly contradicted the zeitgeist of shrinking government and muscular conservatism: it classified AIDS as a disability eligible for welfare benefits, both through Title II of the social insurance program and the means-tested Supplementary Security Income (SSI) program. The Centers of Disease Control had recently classified AIDS as a disabling syndrome, and the SSA took the CDC’s definition, including conditions such as Kaposi’s Sarcoma, pneumocystis carinii pneumonia

(PCP), and a number of other infections all “at least moderately predictive of a defect in cell-mediated immunity occurring in a person with no known cause for diminished resistance to that disease.”²⁷ The definition – and the crisis itself - suited Social Security bureaucrats in several respects. It defined disability very narrowly, limiting AIDS to conditions that could not be explained in otherwise “healthy” men except through catastrophic auto-immune failure. Every CDC-defined case up to that point had involved individuals totally incapacitated and terminally ill, suggesting the financial liability for state and federal governments would be manageable. The SSA’s official definition of disability for the purposes of granting access to welfare benefits was of a person unable “to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which can be expected to result in death or has lasted, or is expected to last for not less than 12 months.”²⁸ Yet the crisis arose just as the SSA was under fire for conducting a heavy-handed and shambolic purge of the SSI rolls, empowered by hastily-conceived legislation passed in 1980 and encouraged by a federal administration keen to shrink the welfare bill.²⁹ A huge number of contested cases had reached the Courts, which tended to find in favor of the plaintiffs, and so welfare bureaucrats had little to gain by stalling on recognizing a disability that was clearly ending the productive lives of a limited segment of the population. At the same time, however, the SSA had no incentive to expand benefit rolls beyond the narrowest confines suggested by existing CDC research.

People with AIDS in 1983 were usually extremely ill at the point they applied for benefits. They were required to apply to a local branch of the SSA. It was possible in some larger cities to phone and ask for forms to be mailed to applicants for completion, but those forms still needed to be completed and returned. The SSA branch office would make the determination of financial eligibility. Once that hurdle was successfully jumped, the application would be sent to the nearest state-run disability determination office in the

applicant's home State, whose job was to gather the medical evidence that the applicant had an SSA-approved opportunistic infection that rendered him or her unable to undertake "substantial gainful activity." In theory, AIDS was classed as a disability eligible for a "presumptive diagnosis" that allowed for benefits to be paid before the full medical documentation had been received, and benefits could be backdated to the original date of application.³⁰ But in practice the devolved bureaucratic process varied wildly from office to office, with some refusing to view PWAs as presumptively disabled, and others requiring detailed hospital records instead of just a transcript of a phone conversation with a physician normally required for a PD classification. One applicant in Georgia, almost blind with cytomegalovirus and riddled with herpes simplex, both SSA listed opportunistic infections, was subjected to a functional test in which he was asked to lift 10 lbs and thereby declared fit to work and not disabled. Local disability offices in Manhattan, by contrast, were much more liberal, partly because of the presence of a well-mobilized set of gay rights organizations to lobby on patients' behalf, and also a consequence of long-established variations between States and localities in the generosity of welfare programs. In most states Medicaid eligibility automatically followed from SSI, but waiting for the SSA to send the files on to state Medicaid offices was not advisable. Savvy claimants (often assisted by AIDS advocacy organizations) would apply directly to their state Medicaid office, requiring yet another round of form filling and visits to government offices. "The trial of the application process – standing in long lines etc – having to pursue aggressively the records needed for medical and financial verification, is sometimes beyond the physical and mental capabilities of those most severely impaired by AIDS," noted members of the National Gay Task Force AIDS program in May 1984.³¹ Out of an estimated 3,500 people with conditions meeting SSA's criteria of AIDS in the year after its ruling that AIDS qualified as a disability, 909 had managed to file an application for welfare benefits. Many of those, assisted by AIDS organizations in New

York and San Francisco and able to access their medical histories and financial records without huge difficulty, were gay men, begging the question of whether the welfare system was responding to other, less well mobilized, patient populations.³²

Historically, unskilled working-class Americans had secured an easier purchase on disability welfare politics, as they were better able than skilled workers to prove their unfitness for available employment.³³ The AIDS crisis turned this on its head, as many gay men, often previously relatively privileged and privately insured, could access an enviable array of advocacy groups to help them negotiate the welfare system and gain Medicaid coverage. In December 1984, Shanti San Francisco began providing a Medi-Cal case worker to assist clients make applications and “help straighten out any problems you may be experiencing with the monster commonly known as Medi-Cal.” The local office of the SSA also agreed to send an official once a week to assist PWAs with applications, a move Shanti saw as “a major victory for People with AIDS, as the Social Security Administration for the first time is seeking a liaison relationship with us.”³⁴ Gay Men’s Health Crisis in New York set up an office to process disability claims itself before delivering them to the local SSA office, assisting applicants with their forms and initially even vetting supporting documentation. It also operated a “buddy system” of volunteer helpers for PWAs, whose duties including filling in SSI application forms.³⁵ GMHC rapidly found itself overwhelmed by its caseload, but the fact gay rights organizations were able to establish formal conduits into the federal welfare bureaucracy points to the political capital they could harness and partly explains their ability to shape social policy to their needs in ways other populations affected by AIDS could not.³⁶

Even well-organized activist networks had to contend with a welfare bureaucracy determined to contain costs and prevent a public health crisis adding potentially unlimited numbers to the disability rolls. In May 1984 a delegation from the NGTF met the Acting

Director of the SSA and her staff to discuss the increasing incidence of cases of men suffering what had become known as AIDS Related Condition (ARC), a series of medical conditions affecting HIV-sufferers that were debilitating and disabling but which did not conform to the Center for Disease Control's official definition of AIDS. In their presentation to SSA staff, NGTF members emphasized the problems inherent in the cumbersome eligibility confirmation process. "The implications in terms of medical care can be quite serious: since in most states eligibility for Medicaid depends on having been approved for SSI, inordinate delays in SSI has in some cases caused medical care to be withheld... In addition to these tangible effects on the quality of life and medical care, the uncertainty and worry that result from lengthy and sometimes inexplicable delays translates into additional psychological stress which can sometimes hasten the decline of the claimant."³⁷

The NGTF's interaction with the SSA offers important evidence of the powerful forces acting to limit state responses to a public health emergency. While the fact the meeting took place demonstrates the capacity of activist groups to influence the terms of the policy debate, NGTF negotiators quickly found themselves forced to conform to a carefully scripted and restrictive language of welfare rights in the hope of winning minor policy concessions. Their briefing document, written prior to the meeting to plan how to structure their demands, collated specific examples of people with AIDS-related conditions being denied benefits, and argued that many were "disabled: suffering from debilitating fatigue, and lymphadenopathy that may be so severe as to restrict movement." The authors also noted that many of these cases saw a rapid decline in their condition to the point that they quickly contracted an opportunistic infection recognised as AIDS by the SSA, and even that "denial of benefits hastened their decline." The negotiating group put forward a number of suggestions for improving the evaluation process and for using best practice (usually in New York) as a model to be rolled out in other disability determination offices. But they stopped short of

recommending a wholesale expansion of the SSA definition of AIDS on the assumption the SSA would immediately recoil from such a move. Attendees were urged to avoid “appearing to suggest that all promodromal persons – which might number in the tens of thousands – are necessarily as ill as those with CDC-defined AIDS. In fact they probably aren’t – only some fraction of ARC will be in need of benefits. For this reason it is not wise to raise the question of [presumptive disability] for ARC claims – leave that and other details for the doctors to resolve.”³⁸ This confused and contradictory amalgam of professed expertise on the limits of the welfare state, combined with a language of financial conservatism and a deferral to medical experts, blunted their message. It ensured crucial issues at the heart of the crisis, notably who remained invisible in the public debate over disability and AIDS, would remain unaddressed.

That both key AIDS activists and SSA administrators articulated the role of the welfare system using a sliding scale of infirmity that privileged more apparently “disabled” people over others ensured there would be a slow response to an epidemic that was as much a crisis of race and class as one of sexual dissidence. Disability politics had long privileged the notion of visibility in assigning welfare funding: an obvious manifestation of infirmity such as missing limbs was much easier to categorize than chronic fatigue, for example.³⁹ A review of SSI commissioned at the end of the decade reaffirmed the agency’s commitment to defining presumptive disability as “when there are readily observable severe impairments such as amputation of extremities. The field offices also have the authority to make a finding of presumptive disability for claimants with HIV infection whose disease manifestations are of a severity listed in the regulations.”⁴⁰ Early in the epidemic opportunistic infections such as pneumocystis carinii pneumonia had proven to be deadly, and a person’s descent into infirmity rapid and highly visible. But at no time in these early years before the formation of ACT UP did the SSA or activists in groups like the NGTF look to a host of opportunistic

infections not always as readily visible or as easily associated purely with AIDS as they were with poverty, including certain forms of tuberculosis. Indeed, though TB was the single largest disease associated with HIV infection worldwide, it was not even on the CDC's list in the 1980s, despite the clear evidence associating HIV with TB in poor communities of color, such as Belle Glade in Florida.⁴¹ This is not to argue communities of color did not organize and establish their own activist support networks.⁴² Rather, it is to highlight the obvious limits to an advocacy politics delineated by separate minority interests and by appeals to a state bureaucracy determined to contain a potentially nightmarish health crisis to as small a section of the population as possible.

The mid-1980s witnessed the unfortunate coincidence of a public health emergency occurring at a time when the Reagan administration was placing the SSA under severe pressure to continue removing people from the disability rolls. After a long period of interim directors, the administration in 1986 appointed Dorcas Hardy as Commissioner of Social Security, an old Reagan associate from his gubernatorial days. Handed a speech to deliver soon after arriving at the SSA, Hardy crossed out a paragraph devoted to SSI with a comment in red ink, "No mention of SSI in my speeches! I am NOT the welfare queen."⁴³ Her appointment came as the SSA was already under fire from a number of state governments for flouting a 1984 law passed by Congress to make it more difficult to throw claimants off the rolls. In many cases the federal reviews, supposedly subject under the new law to clear medical evidence of an improvement in a claimant's condition, were ignoring the "medical improvement" guidelines and instead simply asking whether the claimant could now undertake work, thereby discounting the original disability determination, in clear breach of congressional intent.⁴⁴ The political climate was hostile to attempts to adapt the federal AIDS disability criteria to a rapidly evolving epidemic.

On February 11 1985, the Social Security Administration published an unequivocal statement in the federal register that state disability offices should all uniformly consider a person with CDC-defined AIDS presumptively disabled and able to access SSI benefits immediately pending final medical verification. In one sense constant lobbying on the part of gay rights organizations and their handful of allies in Congress had made an impact. The SSA ruling made clear that it considered AIDS a catastrophic disability eligible for welfare funding because PWAs “experience severe illness from infections or diseases which ordinarily do not have serious effects on or do not occur in healthy individuals. In individuals with AIDS, these infections or diseases have been reported to have an exceedingly large death rate.”⁴⁵ Between February 1985 and the fall of 1987, some 17,000 PWAs were granted benefits, dwarfing the barely 1,000 applicants in the first year of SSA coverage. Only 5,560 remained claimants at the end of that period, with the SSA assuming the rest had died.⁴⁶ Yet the SSA ruling did not add any opportunistic infections to the AIDS definition, did not mention ARC as an issue, and persisted in viewing eligible conditions as only those outside the experience of “healthy” people, and so likely to exclude many of those on the margins of society and invisible to CDC scientists.

Gay rights groups did not give up the fight to widen the AIDS definition so as to smooth the pass of PWAs to welfare coverage, but their appeals to scientific integrity differed little from the CDC in privileging gay white males. As institutional paralysis and the ongoing political confusion over how to tackle the epidemic left many PWAs marooned in a welfare no-man’s-land, the Scientific Affairs Committee of BAPHR in late 1985 devised their own medical definition of ARC, which they sent to CDC. Pointing out that the “lack of a universal definition of this complex of medical findings [has] complicated delivery of health care, insurance coverage, and disability classification for these patients, who may be as disabled or more disabled than some patients with the full-blown Acquired Immune Deficiency

Syndrome,” the committee proposed a new working definition of ARC based on a range of observed major and minor clinical findings. Yet the suggested definition demonstrated precisely the problems inherent in using epidemiological data as a platform for assigning social services. The clinical conditions identified, such as lymphadenopathy, oral thrush, and hairy leucoplakia (the latter far more likely to present in men), only represented typical conditions in the male patient sample, and, as would later become clear, did not adequately represent the full range of conditions apparent once the epidemic spread into other populations. Furthermore, those clinical conditions – and no fewer than two major and two or more minor were suggested as definitive – were set alongside a required immunologic set of criteria (including t-cell count), and laboratory findings (such as the presence of HTLV-III antibodies, what would soon become HIV). The doctors, careful to frame their case in terms they felt state authorities would accept, refused at that point to advocate the use of T-cell count, the clearest marker of medical conditions associated with AIDS, to define the disease. They recognized the need to engage with the federal government through identifiable diseases that could classify and regulate recipients of public welfare. Telling, too, was the assumption in the BAPHR definition (as in that of the CDC) that “other established causes of the abnormal findings have been ruled out” when determining the ARC diagnosis.⁴⁷ As in the case of the NGLTF’s negotiating strategy with the SSA, BAPHR doctors framed their claims to expertise and political authority within boundaries set for them by the state. The idea that doubt could be dispelled when defining medical causes of disability, particularly when analysing a still poorly understood medical phenomenon, reflected CDC policy but not the reality of an epidemic that would not remain within the neat parameters set out by those with an interest in containing its impact.

The SSA in Baltimore firmly opposed expanding the definition of AIDS because it could not evaluate a constant and definite level of disability in ARC cases (including “severe

disabling fatigue,” lymphadenopathy, chronic oral thrush, among others) that could be measured and validated. Commissioner Hardy wrote Los Angeles State Senator David Roberti, whose office managed much of California’s campaign for better resource for AIDS patients, that the “prognosis for individuals with ARC is not as consistently and uniformly poor as is the situation with AIDS. While some individuals with ARC are unable to work and, therefore, would be eligible for benefits, others may be far less impaired.” She emphasized “the need for documentation of specific signs and symptoms and...describing limitations of function, such as might be evident from a detailed description of the claimant’s daily activities over time.”⁴⁸ In other words, ARC sufferers had to enter the complex web of surveillance and control overseen by the SSA in which their lives would be picked over by bureaucrats authorized only to distribute meagre resources to those classified as fundamentally disabled and effectively helpless. Gay rights activists were forced to reconcile – not very straightforwardly – identity politics built upon social acceptability and a welfare politics long the preserve of the social outcast.

In July 1987 the SSA finally relented to include some ARC symptoms as eligible for disability assistance, and hence Medicaid. This followed two years of pressure from Congressmen and senators with large constituencies of ARC sufferers, many of whom reported getting the run-around from the agency’s local offices because they could not prove the severity of their condition.⁴⁹ Patrick Kelson, a San Francisco constituent of Nancy Pelosi, one of the main champions of a widened SSA definition of AIDS, gave a harrowing account of his life with so-called ARC. “I don’t *look* sick, and so I am told by the Social Services Department that I should be able to work an 8 hour day, and therefore ineligible for *any* type of assistance whatsoever....I have no job, no checking account, and no savings account. Any property that I have had has been sold a long time ago. Now I have lost all my medical coverage.” He painted a vivid portrait of the exhaustion that had left him unable to function,

“sometimes not to be able to move because of the pain, and to a mental examination of that pain, to determine what medications might be required that day, and then to determine if your stomach will accept them, assuming that you can swallow them because your mouth may be too raw and sore due to leukoplakia sores”.⁵⁰ The Harvey Milk Democratic Club in Pelosi’s district set up a phone line to collect details of ARC cases, and on March 28 1988 put out a press release detailing some of the horror stories and the evidence they had obtained of a deliberate SSA policy to keep the benefit rolls down. “A Social Security case worker told the Milk Club there was a ‘monthly quota’ of cases that were ‘approved on the initial go-round.’ All cases above that number are denied and forced to go through the lengthy appeal process.”⁵¹

In June 1987 the CDC responded to activist medical groups like the Bay Area Physicians for Human Rights, together with its own gay employees, and amended its official definition of AIDS to widen the list of associated illnesses to include emaciation and dementia, and pressure was brought to bear on the SSA to follow suit. It took two months to do so, with senior policy advisor at SSA Bruce Shoebel initially arguing that “these conditions would not automatically qualify victims for Social Security benefits because it is not clear that having these two conditions [emaciation and dementia] precludes individuals from returning to work at some point when the condition is under control or in remission.”⁵² San Francisco’s two congresswomen Nancy Pelosi and Barbara Boxer took the lead in putting pressure on the SSA and took credit for the sudden volte face at the end of July.⁵³ In so doing, they were explicitly rejecting the state bureaucracy’s definition of disability and widening the potential pool of the eligible needy even as Medicaid was coming under severe financial pressure.

The expansion of the Social Security AIDS definition to include some, but by no means all, the conditions associated with the virus highlighted the severe limitations of a

social welfare system underpinned by disease categories and an overwhelming imperative to deny coverage if at all possible. The categories chosen – emaciation or wasting syndrome and dementia – were the product of a strategy on the part of government agencies of identifying conditions unlikely to have any other underlying cause than AIDS. They also reflected the emphasis placed by AIDS activists on illnesses commonly presented by their own principal client group: gay men.

By the time the SSA expanded their AIDS definition in the summer of 1987, it had become clear that the epidemic had spread far beyond the narrow confines within which state bureaucrats had consigned it. The US Public Health Service estimated that year that between one and 1.5 million Americans were HIV-positive, and that 9,000 cases of AIDS had been diagnosed in New York City alone, excluding the many thousands who did not fit the CDC definition. “By 1991,” argued New York City Health Commissioner Stephen Joseph in February 1987, “the impact of the AIDS epidemic on our citizens, our hospitals, and the entire city will be beyond that of any public health crisis in modern times.” Thirty-six percent of New York City’s caseload were IV-drug users, up from twenty-two percent in 1981, and many of these cases presented with illnesses not associated with CDC-defined AIDS. Joseph tentatively sketched out the emerging link between HIV status, poverty, and drug abuse, and dramatic rises in rates of TB, pneumonia, and endocarditis, illnesses not identified in CDC surveillance exercises.⁵⁴ Many of those representing minority populations had long protested the “limitation of the monocultural physicians and other health professionals directing public and private efforts to contain the AIDS epidemic,” complaining that “some of these professionals proceed on the implicit assumption that the white, English-speaking population coincides with the universe in which the AIDS virus operates.”⁵⁵ Many poor minority populations had limited access to health services, and where they did have access to dedicated clinics, as in Ward 86 of San Francisco General Hospital, African American

activists reported being “particularly concerned with minority cases because their health care and social services needs are not currently being met....Intravenous drug users, for example, are not typically gay, and many have trouble receiving information about AIDS that is primarily directed at a gay audience. Ward 86 has been slow to recognize this.”⁵⁶ Doctors, many ignorant of the variety of illnesses indicative of HIV infection, often misdiagnosed minority patients, who were excluded from medical trials and the collection of statistical data in hospitals.⁵⁷

The creation of ACT UP in 1987 drew in activists from a range of backgrounds, including those working with the poor, allowing for a more diverse range of voices around AIDS treatment issues. Terry McGovern, a civil legal services lawyer who witnessed the interface of poverty and illness during the epidemic, later recalled that her work in poverty law revealed the multiple barriers between minority PWAs and the health care and welfare systems. In her opinion, gay male groups lacked expertise to deal with poverty law issues that constituted “a whole separate field.”⁵⁸ McGovern attended her first ACT UP meeting in the aftermath of the ARC definition change, recalling: “what I saw were all these women who couldn’t qualify for benefits...And then they were dying before they qualified....And then, so I go to ACT UP, and these women are like, oh, the CDC definition of AIDS excludes women.” As she took on more cases of women denied disability benefits because their conditions did not fit the CDC definition, she encountered an ever widening pool of people excluded from a welfare state that had responded fitfully to one health crisis – a gay male one - while ignoring others. “So this was hugely important,” she later recalled, “to get that definition expanded for women, and also for low-income people. [E]verybody always focuses on women because that was very obvious. But the original AIDS definition was not looking at the concept of converging epidemics. So tuberculosis wasn’t in it; bacterial pneumonia wasn’t in it. So it wasn’t just women; it was lots and lots of poor people, if you had to pick a

denominator.”⁵⁹ While cognizant of the many differences between various populations of PWAs, McGovern articulated the common thread tying together those who were not white males: a lack of access to quality health care, susceptibility to medical conditions outside the CDC and SSA’s AIDS definition, and their desperate need for strong voices to advocate on their behalf.

That the battle to widen the debate over welfare and health access for PWAs was likely to be difficult became clear when the Social Security Administration served notice that it fully intended to resist efforts to expand the welfare caseload. The SSA had attempted to resist pressure to follow the revised CDC AIDS definition in June 1987, predicting a rise in cases of some twenty percent, arguing that “we never intended to extend benefits simply based on a diagnosis, but rather on a basis of a person’s ability to work.”⁶⁰ Earlier SSA policy had assumed that the CDC definition encompassed diseases that were universally debilitating and a clear path to an “extremely high death rate,” but the inclusion of new categories of disease at a time of significant hostility to welfare programs on the part of the Reagan administration made administrators very nervous.⁶¹ Once they agreed to expand the definition in July, the SSA set about trying to head off any further changes. In September they issued a new ruling that broke the link to the CDC definition of AIDS. In a clear indication of bureaucratic irritation at the recent definition change, the note stated that “CDC defines AIDS for health and other purposes that are not necessarily intended to have prognostic significance nor to designate the severity of the illness. By contrast, SSA must determine if the disability requirements of the law are met. Moreover, SSA has no control over possible future changes in the CDC definition...”⁶² It was clear that the notion of “control” when dealing with welfare policy was synonymous with restricting access. The CDC definition change had come just at the moment the campaign for welfare access for those with HIV was diversifying, and as the number affected by the epidemic was climbing inexorably. “Prior to

the revision,” noted an ACT UP background paper, “67% [of cases] were homosexual/bisexual men, and 23% intravenous drug users. In the first year following the revision, the percent who were intravenous drug users, both homosexual and heterosexual, increased to 43%. Blacks increased from 24% to 36%. Hispanics from 13 to 16% and women from 2.6% to 3.6%.”⁶³ The SSA’s initial categorization of AIDS limited it to “illnesses...not found in healthy individuals, or if they occur, the illnesses are relatively mild.”⁶⁴ The SSA had from the beginning viewed AIDS as a disability through its easily observable – and by definition rare - defiance of nature, its ability to mark out afflicted young men from their “healthy” compatriots. A rapid diversification of those affected, suffering illnesses that were neither rare nor restricted solely to those with HIV, threatened to undermine decades of restrictive and punitive welfare policy. That many of those clamoring for access by the late 1980s were already heavily stigmatized in social policy debates would make their engagement with the federal bureaucracy all the more challenging.

Expanding the health care debate: gender, race, and class privilege

It was clear that, as the epidemic took hold in non-LGBT populations, a response to the health disaster that downplayed the variety of populations affected would exacerbate tensions in health care and sexual politics over questions of race and class. People of color were not bound together by a sense of economic entitlement or by a politics of sexual solidarity: on the contrary, sexual object choice was not the primary source of HIV transmission for non-whites, and the 40 percent of AIDS cases concerning people of color by the end of the 1980s included women, children of PWAs, and intravenous drug users. They were disproportionately reliant on the ramshackle public health system due to the high proportion of minority patients who worked in jobs without private insurance coverage or outside the regular employment market. “The simple fact is that AIDS is just one of many epidemics devastating minority communities,” explained the Executive Director of the

National Minority AIDS Council in September 1987. “In minority communities, it has been placed within the context of other social, economic, and political crises... [They are] subjected to the inequities of our health care system and the disadvantages created by fewer educational and job opportunities.”⁶⁵ A 1985 report of the Secretary of Health’s Task Force on Black and Minority Health noted that access “to quality health care is problematic for many minorities who are over-represented among the poor, live in medically under-served areas, and who are more likely to rely on Medicaid and other public assistance.” African Americans and Latinos constituted 19 percent of the US population but 25 and 14 percent respectively of AIDS cases.⁶⁶ And the overriding issue for these populations was not a politically constructed sense of “community” but one of economic powerlessness.

Minority activists sought to emphasize economic disempowerment as a way of broadening the health care debate and reconfiguring it for minority populations reluctant to associate themselves with queer activism. Reggie Williams of the San Francisco-based organization Black and White Men Together emphasized the need to place socio-economic struggles of minorities into the debate on AIDS treatment, arguing that “many people in the minority community have the impression that the organizations assisting people with AIDS are, once again, serving a white, middle class, gay male population. This is true both because these organizations are composed of white people on their staffs and serve a mainly white clientele.”⁶⁷ Much material produced by this organization highlighted the glaring racial inequalities in health care provision, but minority activists also saw a problem at the interface of race, economic power, and sexual identity. “The case can readily be made that gay men of color are alienated from the mainstream health care system,” claimed the authors of a grant bid to the San Francisco City AIDS Office for an early intervention project for minority gay and bisexual men.⁶⁸ The political strategy of associating a “middle class” with white privilege both represented the reality of the close association of race and class in the United States, and

was a consequence of queer activists' desire to make performative protest a larger part of their campaign than economic inequality.

Reggie Williams noted that one “of the biggest problems with Black people, because we don’t have affordable incomes that would allow good health care, is we end up at the General Hospital subsequently we don’t go until we are at our sickest point, when it’s already almost too late.”⁶⁹ His organization pointedly refused to join ACT UP’s boycott of the Sixth International Conference on AIDS in San Francisco in 1990, arguing that with “African Americans having a history of continued deficit in health care in this country, the...conference is not one for BWMT-SF to boycott.”⁷⁰ For those at the bottom of the economic ladder, the public hospital was the principal point of connection between the sick individual and the health care system, and these patients would not be reached by a campaign of public education that privileged sexual identity and a concomitant language of civil rights. “You can reach people through private doctors, hospitals, health departments, and the mass media,” stated George Beschner of the National Institute of Drug Abuse. “But for the inner-city heroin addicts, their primary source of medical help is the emergency room. They don’t receive media messages that are directed at the middle class.”⁷¹ In the struggle for access to health care for those with AIDS or a related condition, sexual identity, class and race coalesced around the political question of the future of the public health system.

Those central to the struggle to expand access to public welfare were quick to make the connection between poverty and exclusion from the disability debate in AIDS politics. Many, like Terry McGovern, were women. Her work as a poverty lawyer had exposed her to the daily horrors of a population missing from debates over access to SSI and Medicaid, leading to her opening the HIV Law Project just at the point she began going to ACT UP meetings. “I was seeing extremely sick people,” she recalled. “Women, gay men of color, who lived in the projects, who wouldn’t say they had HIV/AIDS, but they were clearly dying

of HIV.”⁷² Others became active after hitting the wall of an unflinching bureaucracy themselves, like Keri Duran, a Massachusetts lesbian who could not access the public health system after contracting the virus through drug use.⁷³ They and others brought their experiences of exclusion to ACT UP, where they joined forces with AIDS activists fresh from the experience of battling for an expanded SSA disability definition, but who remained trapped in a political discourse around entitlement that no longer reflected the epidemic’s reach. Maxine Wolfe of the Women’s Committee recalled of the campaign to widen further the CDC definition of AIDS-related conditions in the early 1990s, “there were gay men, there were women of color, straight women of color, lesbians of color. There were straight women. It was every possible kind of person came together to work on that thing, that that’s what was amazing about it.”⁷⁴ ACT UP’s loosely organized entrepreneurial structure allowed new strategies and campaigns to emerge over time. The problem was a public discourse on welfare that depended on categorization of people: bureaucrats in CDC and the SSA understood that to challenge that was to risk undermining an entire system for allocating who could and could not receive public benefits.

One factor that shifted the focus of social welfare activism within AIDS politics towards women and poverty at the end of the decade was the evidence of the changing demographics of the epidemic. In 1989 the Broward County, Florida, Public Health Department recorded 94 female AIDS cases, 17 percent of the total, compared to just three five years earlier, and in April 1990 reported receiving ten new female cases a month. In part, these statistics were an uncovering of a hitherto hidden aspect of the epidemic. “When a women shows up with symptoms,” stated Marie-Lucie Brutus of the Brooklyn Women and AIDS Resources Network, “doctors don’t associate the symptoms with HIV infection. Instead, they see them as normal problems women experience, or they see them as a passing matter, or as psychosomatic.” It was not unusual, she noted, for women to see four or five

doctors before getting tested, and women were more likely to fall between the cracks of the health care system.⁷⁵ The Health Political Action Committee Bulletin devoted its main cover article in its Winter 1989 issue to women as “the missing persons in the AIDS epidemic,” as two physicians working in women’s health presented a stark portrait of the ways in which epidemiological tracing of the disease had erased women from the narrative. A common assumption that women were not an at-risk population resulted in regular misdiagnosis, and many illnesses presented in female AIDS patients were not classed as related to HIV infection. Crucially, very few women had been included in drug trials, and the “potential importance of gender differences in response to HIV infection is rarely addressed in current medical publications, and this lack allows only the most rudimentary understanding of AIDS in women. Physicians find little information available to help them understand HIV-related gynaecologic conditions in women.”⁷⁶

Activists in the women’s committee of ACT UP were instrumental in taking these issues beyond the pages of sympathetic newspapers and journals into the realm of political action. The women who formed the vanguard of the campaign brought direct experience of the access and definition problems. “It started out by us doing this Women and AIDS teach in,” recalled Maxine Wolf. “The handbook that we created ... went all around the world....and the teach-in was about the different infections....Well, we did yeast infections, which, of course – all yeast was on the Center for Disease Control definition of AIDS, but not vaginal yeast – like, yeast is yeast. There were various forms of tubercular bacilli, that would form in women, in different places than men....And we did stuff on bacterial pneumonia. We did stuff on cervical cancer.”⁷⁷ The ACT UP Women’s Caucus teach-in in New York in March 1989 published its handbook the following year as a collection of essays exploring the gendered dimensions of the epidemic, publicizing the limits of the state’s response to the crisis. “Statistics,” wrote Risa Denenberg of the Women and AIDS book group, “only count

women who fit into the CDC's narrow definition of AIDS; all the other women just remain invisible."⁷⁸ It formed the platform from which to organize direct political action, first at the Department of Health and Human Services in October 1989 and then, in January 1990, at a two day protest at the Centers for Disease Control entitled "Two Days, Two Ways to Fight for Your Life." Day one protested Georgia's anti-sodomy statutes, upheld by the US Supreme Court in the infamous *Bowers V Hardwick* case in 1986, and the second focused on the official CDC definition of AIDS and ARC. Demonstrations of this kind gave voice to the previously marginalized in the AIDS treatment debate, even if still reported in full mostly in sympathetic fringe publications.⁷⁹

By the end of 1990, women campaigners in ACT UP had taken on the CDC and SSA directly. Terry McGovern and MFY Legal Services launched a class action lawsuit in October on behalf of all women with HIV-related illnesses, charging that the SSA's disability determination policies were discriminatory.⁸⁰ And the ACT UP women's committee pressured the National Institutes of Health to organize a conference on women and AIDS, to take place in December 1990, resorting to a sit-in at NIH's AIDS Division Director Dan Hoth's office.⁸¹ In preparation for the conference, ACT UP produced a revised ten-page critique of the CDC's epidemiological studies of the epidemic, noting that their obsession with defining categories of the afflicted rather than modes of transmission or the full spectrum of related infections guaranteed an inadequate and partial response to the crisis. In failing to conduct epidemiological testing on a wider range of subjects, including women, the CDC was artificially lowering the number of reported cases, "a perfect rationale for overall lowered funding for the epidemic. It avoids the issue of the need for national health care. It can divide one community against the other in fighting for the funding that does exist." Crucially, the CDC was reluctant to include widely reported AIDS-related conditions in its formal definition, such as candidiasis in women, because such illnesses were common

(unlike, say, Kaposi's sarcoma) and so their inclusion would inevitably commit federal agencies to a major intervention in what until that point had been portrayed as a problem only in stigmatized "risk groups."⁸²

This point was clear from a CDC briefing document circulated just a month before the 1990 conference. While this stressed a concern "that all persons with HIV-related diseases should have adequate and appropriate health care," the document baldly claimed that "there is no scientific evidence that conclusively links HIV infection to life-threatening illnesses specific only to women. Certain conditions such as vaginal candidiasis and pelvic inflammatory disease, although sometimes found in women with HIV infection, are not specific for HIV infection and/or immune system suppression."⁸³ The federal government attempted to dress up this airy dismissal of the implications of changing patterns of epidemiology and transmission in the garb of scientific integrity: if a disease not specific to HIV infection was included in the definition of AIDS, argued CDC scientists, then the accuracy of forecasting the epidemic could be compromised. Yet they soon exposed their determination not to find evidence that would complicate their epidemiological assumptions when, in a meeting between a CDC team led by Director William Roper and representatives of Gay Men's Health Crisis, the scientists admitted that CDC had no working definition of a lesbian, had no real interest in exploring the possibility of female-to-female transmission, and simply noted with regret "the difficulty of finding self-identified lesbians for research purposes."⁸⁴ In its reluctance to reorient their examination of HIV epidemiology to include a full range of social contexts, including sexuality, rather than simply risk behaviors (women, according to the CDC, could only fall into four categories for HIV transmission in 1990: as IV drug users, recipients of blood products, practitioners of heterosexual sex with infected men, or as those for whom a risk activity could not be identified) the CDC was attempting to contain an epidemic within immovable boundaries. When it began conducting "spectrum of

Disease” studies in 1989, CDC did not choose cities with the largest numbers of women cases or IV drug users, took 60% of its data from Atlanta as the only city to use multiple testing sites, and admitted that only 7% of the spectrum study cases were women, promising to increase the scope of the studies only if further federal funding became available.⁸⁵ Denying the scale of the epidemic offered a way out to a federal bureaucracy unwilling to face up to the financial and human costs of a social safety net completely unable to cope with an ever-widening public health crisis.⁸⁶

The December conference itself presented women activists with an opportunity to take on CDC and NIH officials on a public stage, and raucous, angry scenes ensued when NIAID Director Anthony Fauci and CDC’s James Curran attempted to downplay their concerns and to dominate the event, toeing the official line. “So, that’s when we wrote up our first women’s treatment and research agenda,” recalled Wolf,

“and we handed it out at that conference ...when Tony Fauci was speaking, and he was basically saying that they didn’t know anything about women and AIDS, but he was going to talk about men and AIDS, and he started doing AIDS 101 – all hell broke loose. And they had written up a whole statement about... the three things that they needed[:] they needed the CDC to change the definition of AIDS. They needed women in clinical trials, and they needed to get their disability payments.”⁸⁷

The angry scenes at the December conference and the unfolding lawsuit marked the launch of a coordinated, organized assault on an official AIDS definition that denied benefits and treatment to thousands of women and people in poverty. The Center for Women’s Policy Studies successfully sponsored a resolution urging passage of several congressional bills to tackle AIDS and women, including the Social Security and SSI AIDS Disability Act, which would require the SSA to adopt an interim definition of HIV disability that reflected the full

range of symptomatology and not just the CDC definition.⁸⁸ ACT UP fought with some success to gain access for women and people of color to drug testing as well as expanding access to welfare benefits.⁸⁹ Activists continued to launch demonstrations and protests to force the CDC, and then the SSA, to change its AIDS definition to include a much broader range of illnesses and a general T-cell count of under 200. The CDC announced in November 1991 that it would accede to the demand for the T-cell count as a definition of AIDS, but held out against naming specific diseases, and the SSA followed its lead the following month. AIDS activists were divided over how far to push the government, but it was evident that many PWAs were desperately ill and in need of disability benefits without the low T-cell count.⁹⁰

The SSA's implementation of new disability rules relating to AIDS demonstrates the extent to which government bureaucracies remained committed to using the principle of categorical assistance rather than universalism as a means of exclusion in social policy. Although the new December 1991 guidelines included new diseases in the SSA's definition of AIDS, including certain manifestations of cervical cancer, they still excluded many others activists had campaigned to have included, such as pelvic inflammatory disease. More restrictive, however, was the new requirement of a two-pronged "functional test" for those seeking a disability diagnosis in order to receive benefits. The SSA now required a primary physician to fill in forms assessing claimants' "functional limitations," and also required claimants with many newly-included conditions (and even some already recognized diseases, such as KS) to demonstrate multiple illnesses, or to show evidence that the illnesses were "recurring" or "not responding" before they could receive a cent in benefits. Thus the bureaucratic policing of the welfare system, using doctors and State welfare offices as intermediaries, was ramped up significantly in order to offset any widening of the potential pool of claimants.⁹¹ The new regulations were rushed in without a standard consultative

period, and were predicated on the assumption – established in their break with the CDC definition in September 1987 - that whereas the CDC defined illness, SSA had to define disability, and now possessed the administrative experience of almost a decade managing AIDS definitions with which to enlarge its regulatory oversight.

The heavy-handedness of the new guidelines produced howls of protest, not so much from activists who had fought to secure any change at all, but from those who would have to implement the onerous changes, including state-level social services departments. “The proposed change... would require a more detailed and probing assessment of the individual’s daily activities, social function, task performance and a documented history of repeated episodes of decompensation,” wrote Gregory Kaladjian, acting commissioner of the New York Department of Social Services, to Social Security Administration Commissioner Gwendolyn King in a six-page critique shortly after the introduction of the new regulations. “Disability is defined as the inability to engage in substantial gainful activity, the inability to work. The functional criteria indicated in the listings go far beyond precluding employment. They delineate a portrait of an individual who is unable to accomplish basic normal functions for independent living.”⁹²

Kaladjian followed up this forensic dissection of the new SSA rules with a personal letter to King, pointing out their disproportionate impact on the underprivileged: “Obtaining the necessary documentation will be an onerous, if not impossible, task for many poor people who get their health care in overburdened public clinics....I believe that applying SSA’s new listings will result in denying thousands of people who previously would have qualified for disability benefits. Thousands more will need to be catastrophically debilitated before being determined disabled.” States would have to go through the costly rigmarole of conducting the risk assessments on the SSA’s behalf, find many claimants ineligible for federal benefits, and then watch them fall back on the meager resources of the states themselves. “It is difficult to

understand,” he concluded, “why SSA would choose to deal with the escalating HIV crisis by making it more difficult for many individuals with HIV disease to obtain critically needed federal disability benefits.”⁹³ Members of the National Commission on AIDS, set up by Congress in 1989, also wrote to King in January 1992 and met with SSA representatives to express serious concern about the use of functional tests designed to assess mental, rather than physical, illness. Yet even this gathering of appointees of the President and Congress could not force the SSA to retreat from its assumption that anyone claiming federal funds had to be proven to be effectively helpless in order to be deemed deserving.⁹⁴

Executive Director of the National Association of People with AIDS William Foreman in his testimony to a Congressional subcommittee that April came close to articulating the dynamics at play. The epidemic was becoming increasingly complicated and involved an ever more diverse subset of the population, at the same time as the federal bureaucracy had more time and space to put together regulations to maintain long-standing divisions between the deserving and undeserving in federal welfare policy. “The rules are a hellish cross between an old Chinese restaurant menu and IRS tax form instruction,” he argued. “They are time-consuming, exhausting – and certainly pointless for a fatal disease which has begun to show end stage symptoms.” As the affected population widened beyond gay men into an as yet undetermined number of the underprivileged, the SSA was removing what had previously been an initial presumption of disability and attempting to restrain federal liability, fearing a potentially endless stream of claims from populations previously scarcely visible to the nation’s social services system. Foreman was optimistic that the new system would “collapse of its own weight,” but in part this was because the patient population would “continue its inexorable shift from privately-doctored middle class gay, white males to a poor minority, inner-city population (medically-served, if at all, by understaffed public clinics, emergency rooms, and Medicaid mills)”: in other words, the

government's determination to police the welfare class would founder on the rocks of its own unwillingness to fund a medical system for the underprivileged with the capacity to undertake the policing. In the meantime, however, "the overloaded system will continue to totter into paralysis; and thousands will suffer delays in securing essential living expenses and medical care."⁹⁵

Recasting the "straight state."

Much of the history of queer activism's engagement with health care in the 1980s has been about empowerment and resistance to the callous indifference of the Reagan administration. We know much about ACT UP, sit-ins and die-ins, campaigns for access to experimental drugs, buyers clubs, and demands for equal rights for sexual minorities, not least the end to sodomy laws that were still in place in numerous states until 2003. But we know much less about the relationship between sexuality and the welfare state, especially after the 1970s when Canaday's book ends but when sexual difference in society became impossible to ignore. A focus on the state and on how health care is delivered and paid for allows us to understand two things. First, efforts to integrate sexual minorities into a resolutely heteronormative welfare state, one in which men were expected to be breadwinners and impoverished women were only deserving of state assistance if they were mothers, reveal the need for historians to link together multiple narratives of civil rights and economic inequality. Secondly, the American state is never passive or "weak" in the face of social problems, even at a time of sustained attack on the welfare state.⁹⁶ State bureaucracies – people within them – make decisions, including the positive decision to make AIDS a disability as early as 1983, and also the decision not to update or improve that policy despite compelling evidence of its grotesque inadequacy. ACT Now, an umbrella organization of all ACT UP branches and various other activist groups, recognized the limitations of the welfare system in noting that the "uninsured are...forced to rely upon a political system that has been

historically unresponsive to the needs of the poor, people of color, the undocumented, women, children, gay men and lesbians – the very people who make up the bulk of the uninsured.”⁹⁷

Charting the evolution of debates over health care for people with AIDS after the 1960s encourages us to reconsider easy teleological narratives about the decline of liberalism or its fracturing into easily defined “identity groups”, and also points to a more contested social politics of gender, sexuality, and public health than had been possible when the American social safety net was constructed between the 1930s and 1960s. Politicians and activists, together with state agencies, gradually and fitfully integrated sexual minorities into older categories of “deserving” in federal welfare politics, leaving a state that was no longer as much “straight” as ever more determined to close down universal claims to the public purse.

¹ *Vector Survival Manual*, 1975, Gay Health Project (1975) Papers, 97-31, GLBT Historical Society, San Francisco, folder 1 of 1.

² Dr Walter Lear form letter, nd, and accompanying resolution “Homosexuality and Public Health,” in Gay Health Project Papers.

³ *Gay Community News*, 1 April 1978, Fred Fejes Papers, Box 4, GCN 8/13/77-12/88 file, Stonewall Library, Fort Lauderdale, Florida.

⁴ APA resolution quoted in Robert Gibson, President APA, to Jimmy Carter, 14 March 1977, Jimmy Carter Papers, Margaret Constanza’s Subject files, Box 4, folder 14; Margot Canaday,

The Straight State: Sexuality and Citizenship in Twentieth-Century America (Princeton, 2009).

⁵ Report of Dr Arthur S. Levine, Division of Cancer Treatment of NCI, in OASH Weekly Report, 7 July 1982, National Institutes of Health central files, Box 74, OASH weekly reports file, National Archives II.

⁶ The SSA's definition of "disability" formed when federal disability insurance was created and then extended to the welfare system in the 1970s was as follows: "the inability to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which can be expected to result in death or has lasted, or is expected to last for not less than 12 months." See Edward Berkowitz and Larry DeWitt, *The Other Welfare: Supplementary Security Income and US Social Policy* (Ithaca, 2013), 32.

⁷ Theda Skocpol, *Protecting Soldiers and Mothers: The Political Origins of Social Policy in the United States* (Cambridge, Mass., 1992); *The Politics of Social Policy in the United States*, ed. Margaret Weir, Ann Shula Orloff, & Theda Skocpol, (New York, 1988); Jacob Hacker, *The Divided Welfare State: The Battle over Public and Private Social Benefits in the United States* (Cambridge, 2002); Gareth Davies, 'The Unsuspected Radicalism of the Social Security Act' in *The Roosevelt Years: New Perspectives on American History, 1933-1945*,

ed. Robert Garson & Stuart Kidd (Edinburgh, 1999), John Ikenberry and Theda Skocpol, 'Expanding Social Benefits: The Role of Social Security', *Political Science Quarterly*, Autumn 1987; Edward Berkowitz, *America's Welfare State: From Roosevelt to Reagan* (Baltimore, 1991).

⁸ Michael Brown, *Race, Money, and the American Welfare State* (Ithaca, 1999); Linda Gordon, *Pitied but not Entitled: Single Mothers and the History of Welfare, 1890-1935* (New York, 1994); Michael Katz, *The Price of Citizenship: Redefining America's Welfare State* (New York, 2002); Alice Kessler-Harris, *In Pursuit of Equity: Women, Men, and the Quest for Economic Citizenship in Twentieth-Century America* (New York, 2001); S J Kleinberg, *Widows and Orphans First: The Family Economy and Social Welfare Policy, 1880-1939* (Urbana, 2006); Robert Lieberman, *Shifting the Color Line: Race and the American Welfare State* (Cambridge, Mass., 1998); Mary Poole, *The Segregated Origins of Social Security: African Americans and the Welfare State* (Chapel Hill, 2006); Jill Quadagno, *The Color of Welfare: How Racism undermined the War on Poverty* (New York, 1994).

⁹ Canaday, *The Straight State*. The 1980s witnessed not only the adaption of the US welfare system to the AIDS crisis, the subject of this article, but also the start of the extension of

corporate domestic partner benefits to some same-sex couples. See Elizabeth H. Pleck, *Not Just Roommates: Cohabitation after the Sexual Revolution* (Chicago, 2012).

¹⁰ See Jennifer Brier, *Infectious Ideas: US Political Responses to the AIDS Crisis* (Chapel Hill, 2009); Deborah Gould, *Moving Politics: Emotion and ACT UP's Fight Against AIDS* (Chicago, 2009); Tamar W. Carroll, *Mobilizing New York: AIDS, Antipoverty, and Feminist Activism* (Chapel Hill, 2015); Martin Duberman, *Hold Tight Gently: Michael Callen, Essex Hemphill, and the Battlefield of AIDS* (New York, 2014); Elizabeth Armstrong, *Forging Gay Identities: Organizing Sexuality in San Francisco, 1950-1994* (Chicago, 2002), chapter 8; Anthony Petro, *After the Wrath of God: AIDS, Sexuality, and American Religion* (New York, 2015); Phil Tiemeyer, *Plane Queer: Labor, Sexuality, and AIDS in the History of Male Flight Attendants* (Berkeley, 2013). One rare example of an effort to examine in detail the public policy response is Ronald Bayer, *Private Acts, Social Consequences: AIDS and the Politics of Public Health* (New York, 1989), but his focus is on the regulation of public health rather than welfare policy.

¹¹ Berkowitz and DeWitt treat the extension of SSI, and by extension Medicaid, to people with AIDS in just over a page: Berkowitz and DeWitt, *The Other Welfare*, 166. Jonathan Engel's three pages on AIDS do not explain how Medicaid expanded to include PWAs, and

focus mostly on the 1990s: Engel, *Poor People's Medicine: Medicaid and American Charity Care since 1965* (Durham, 2006), 215, 233-235.

¹² Teresa A. Coughlin, Leighton Ku, John Holahan, *Medicaid since 1980: Costs, Coverage, and the Shifting Alliance between the Federal Government and the States* (Washington DC, 1994), 21, table 2.5.

¹³ Bruce Decker of the California AIDS Advisory Committee, quoted in "The Politics of AIDS," *Golden State Report*, December 1987, 20.

¹⁴ Cynthia Daniels, *Exposing Men: The Science and Politics of Male Reproduction* (New York, 2006), 6.

¹⁵ See Jonathan Ned Katz, *The Invention of Heterosexuality* (New York, 1995); Jennifer Terry, *An American Obsession: Science, Medicine, and Homosexuality in Modern America* (Chicago, 1999).

¹⁶ Theda Skocpol, *Protecting Soldiers and Mothers*; Linda Gordon, *Pitied but not Entitled*.

¹⁷ Canaday, *The Straight State*, chapters 3 and 4.

¹⁸ See Terry, *An American Obsession*; Ronald Bayer, *Homosexuality and American Psychiatry: The Politics of Diagnosis* (Princeton, 1987); Steven Epstein, "Sexualizing Governance and Medicalising Identities: The Emergence of 'State-Centered' LGBT Health

Politics in the United States,” *Sexualities* 6,2 (2003); William B Turner, “Lesbian/Gay Rights and Immigration Policy: Lobbying to End the Medical Model,” *Journal of Policy History* 7:2 (1995), 208-225; John Dittmer, *The Good Doctors: The Medical Committee for Human Rights and the Struggle for Social Justice in Health Care* (New York, 2009).

¹⁹ On the problematic politics of disempowerment and the construction of artificial and unstable categories of disability, see Robert McRuer and Abby L. Wilkerson, ed., “Desiring Disability: Queer Theory Meets Disability Studies,” special issue, *GLQ: A Journal of Lesbian and Gay Studies* 9, nos. 1-2 (2003); Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York, 2006).

²⁰ See Cathy J Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (Chicago, 1999).

²¹ John D’Emilio in a landmark 1981 essay historicized the relationship between sexuality and economic processes, particularly related to family structure. It is time now to historicize the particular phase of capitalism as it relates to sexuality politics that began with the collapse of the New Deal social and political order in the 1970s. See D’Emilio, “Capitalism and Gay Identity,” republished in Richard Parker and Peter Aggleton, ed., *Culture, Society, and Sexuality: A Reader* (London, 1999).

²² See Engel, *Poor People's Medicine*; Jonathan Oberlander, *The Political Life of Medicare* (Chicago, 2003).

²³ See Berkowitz and DeWitt, *The Other Welfare*, 98.

²⁴ Coughlin, Ku, Holahan, *Medicaid since 1980*, 40-43. In addition, while some programs, notably AFDC, shrank in real terms in the Reagan era, SSI generally kept pace with inflation.

²⁵ "Kaposi's sarcoma in gay males," *Bay Area Physicians for Human Rights Official Newsletter*, July 1981, Bolan Papers, Box 4, folder 3.

²⁶ Denver principles available at <http://www.actupny.org/documents/Denver.html>

²⁷ Definition quoted in memorandum from Ed Power to Mervyn Silverman, "Social service needs of ARC patients," 13 September 1983, Nancy Stoller Papers, UCSF Special Collections, Box 3, folder 33.

²⁸ See Berkowitz and DeWitt, *The Other Welfare*, 32.

²⁹ See Katz, *The Price of Citizenship*, 209-215; Berkowitz and DeWitt, *The Other Welfare*, chapter 5.

³⁰ National Gay Task Force AIDS Advisory, "Applying for Social Security benefits: The Basic Facts," 1983, Nancy Stoller Papers, Box 3, folder 33. State disability offices made disability assessments under contract to the SSA.

³¹ NGTF AIDS program memo to AIDS service organizations, 29 May 1984, “Follow-Up on meetings with Social Security Administration officials,” Nancy Stoller Papers, Box 3, folder 33.

³² *Ibid.*, 2.

³³ The complex dynamics of government disability determinations are explained with enviable clarity in Edward Berkowitz, *Disabled Policy: America’s Programs for the Handicapped* (Cambridge, 1987), especially 46.

³⁴ Shanti newsletter, December 1984, p. 9, Shanti Papers, UCSF Special Collections, Box 1, folder 27.

³⁵ Minutes of meeting of GMHC buddy support group, 3 February 1986, People with AIDS Coalition Records, Box 10, GMHC 1985-88 file.

³⁶ Memo from Jefferson Woodcock, District Manager, SSA in downtown Manhattan to Audrey Hassell of GMHC re Social Security applications, 8 April 1985; Hassell to Woodcox, 3 July 1985; Woodcock to Rodger McFarlane, GMHC, 16 May 1985, GMHC Papers, Box 55, Social Security Administration 1985 file.

³⁷ Memo from NGTF AIDS Program to AIDS Service Organizations, “Follow-Up on meeting with SSA Officials,” 29 May 1984, Nancy Stoller Papers, Box 3, folder 33.

³⁸ NGTF agenda for meeting with Acting Commissioner Martha McSteen of SSA, 30 April 1984, Nancy Stoller Papers, Box 3, folder 33.

³⁹ See Berkowitz, *Disabled Policy*, introduction.

⁴⁰ "Supplemental Security Income Modernization Project: Final Report of the Experts" (August 1992), page 86, accessed at <https://www.ssa.gov/history/reports/ssiexperts.html>

⁴¹ ACT UP information packet "Women don't have AIDS: they just die from it," 6 November 1990, Women and AIDS Papers, Box 1, Stonewall Library; "US targets Belle Glade AIDS care: Federal guidelines issued after workers exposed to TB," *Palm Beach Post*, 22 April 1989.

⁴² See Kevin Mumford, *Not Straight, Not White: Black Gay Men from the March on Washington to the AIDS Crisis* (Chapel Hill, 2016), chapter 8.

⁴³ Quoted in Berkowitz and DeWitt, *The Other Welfare*, 163. One of the authors had served as one of Hardy's speechwriters and had witnessed the incident.

⁴⁴ See testimony of Cesar Perales, New York State Commissioner of Social Services, to House Ways and Means Social Security Subcommittee, 6 June 1985; testimony of New York

Attorney General Robert Abrams to same, 6 June 1985, Moynihan Papers, Box 2076, folder

6.

⁴⁵ Federal Register, Vol. 50, no. 28, 11 February 1985, Rules and Regulations, 5573.

⁴⁶ Memo, "Social Security Disability for AIDS patients," Moynihan Papers, Box 1718, folder

1.

⁴⁷ Press release, BAPHR, 16 December 1985, "Medical Definition of AIDS-Related

Conditions (ARC)," Bolan SFAF Papers, Box 2, folder 25.

⁴⁸ See David Roberti to Dorcas Hardy, 15 September 1986; Hardy to Roberti, 21 January

1987, Stan Hadden Papers, GLBT Historical Society, Box 11, Social Security Administration

file.

⁴⁹ See Nancy Pelosi press release on SSA inclusion of AIDS-related dementia and wasting syndrome in Disability coverage, 28 July 1987, and associated materials, Steve Morin Papers,

GLBT Historical Society, Box 19, folders 5 and 6. California Senator Alan Cranston had also

called on the SSA to widen its disability definition for ARC sufferers in February 1986. See

Stan Hadden to staffers, re San Francisco AIDS Vigil, 28 February 1986, Hadden Papers,

Box 2, memos Jan-June 1986 file.

⁵⁰ Patrick Kelson statement "The ARC Dilemma," Steve Morin Papers, Box 2, file 10.

⁵¹ “ARC patients get federal benefits runaround,” Harvey Milk Club press release, 28 March 1988, Steve Morin Papers, Box 2, folder 10.

⁵² Briefing memorandum for Senator Moynihan “Social Security Disability for AIDS patients,” Moynihan Papers, Box 1718, folder 1.

⁵³ Nancy Pelosi press release, 28 July 1987, Steve Morin Papers, Box 19, folder 5.

⁵⁴ Remarks of Stephen Joseph to Cornell Medical College conference, 26 February 1987, David Rogers Papers, Medical Center Archives, New York-Presbyterian Hospital-Weill/Cornell Medical Center, New York, Box 19, AIDS review file.

⁵⁵ Statement of Lino Zambrano to California AIDS Strategic Planning Commission, “Cultural Obstacles to Controlling the Spread of the AIDS Epidemic,” 26 November 1985, Hadden Papers, Box 7, Minority general file.

⁵⁶ Reggie Williams of the Black and White Men Together group to David Werdegar, San Francisco Department of Health, 20 May 1986, National Task Force on AIDS Prevention Papers, Box 1, Correspondence October 1986 file.

⁵⁷ Letter from National Gay Task Force on AIDS Prevention of BWMT to Paul Volberding of SF General Hospital, nd, National Task Force on AIDS Prevention Papers, Box 1, Correspondence October 1987 file.

⁵⁸ Terry McGovern interview, 25 May 2007, ACT UP Oral History Project, interview number 076, p. 12.

⁵⁹ Terry McGovern interview, 25 May 2007, pp. 15, 24-5.

⁶⁰ “Payments clouded on 2 AIDS ailments,” *New York Times*, 2 June 1987.

⁶¹ *Federal Register*, vol. 50, no. 28, 11 February 1985, rules and regulations, 5573-5574.

⁶² SSA Action note on disability criteria, September 1987, Moynihan Papers, Box 1718, folder 1.

⁶³ ACT UP Network background paper on CDC, People with AIDS Coalition Papers, NYPL, Box 1, ACT UP 1987-91 file.

⁶⁴ SSA note “Update Titles II and XVI – Evaluation of Acquired Immune Deficiency Syndrome,” Moynihan Papers, Box 1716, folder 5.

⁶⁵ For statistics see Reggie Williams to David Werdegar of San Francisco Department of Health, 20 May 1986, National Task Force on AIDS Prevention Papers, Box 1, Correspondence 1986 file. Testimony of Mencer Donahue Edwards of Minority AIDS Council to Presidential Commission on HIV, PCHIV Papers, National Archives II, Box 1, folder 6.

⁶⁶ Background report on minority issues for President's Commission on HIV, PCHIV Papers, Box 6, folder 3.

⁶⁷ Reggie Williams to Roz Abrams of KRON TV, 6 August 1985, National Task Force on AIDS Prevention Papers, Box 1, Correspondence October 1985 file.

⁶⁸ Grant application in EACH Contract proposal 2/90 Initial Early Intervention file, National Task Force of AIDS Prevention Papers, UCSF Special Collections, Box 2.

⁶⁹ BWMT, A discussion with Reggie Williams, NTFAP Papers, Box 4, clippings 1987-89 file.

⁷⁰ Position paper of BWMT on conference, NTFAP Papers, Box 2, position statements file.

⁷¹ Beschner quoted in "Vernacular lowdown on AIDS," *Insight*, December 26 1988-2 January 1989, NTFAP Papers, Box 4, clippings 1987-89 file.

⁷² Terry McGovern interview, 25 May 2007, 11-12.

⁷³ Maxine Wolfe, "Keri Duran, 1964-1995: Lesbian Activists Leaves AIDS Legacy," *Women Alive*, Winter 1995/6, Women Alive Papers, Stonewall Library, Fort Lauderdale, 1 folder.

⁷⁴ Maxine Wolfe interview, 19 February 2004, ACT UP Oral History Project, interview no. 076, p.94.

⁷⁵ "Women and AIDS", *Miami Sun Sentinel*, 5 April 1990, Lifestyle section.

⁷⁶ Kathryn Anastos and Carola Marte, “Women: the Missing Persons in the AIDS Epidemic,” *Health/PAC Bulletin*, 19:4 (Winter 1989), 6-13.

⁷⁷ Maxine Wolfe interview, 19 February 2004, ACT UP Oral History Project, 82-3.

⁷⁸ The ACT UP/NY Women and AIDS Book Group, *Women, AIDS and Activism* (New York, 1990), 4.

⁷⁹ *Ibid.*, 85; “Atlanta 2-day protests to hit Georgia’s gay laws,” *Workers World*, 11 January 1990, 2. The *WW* had covered the epidemic in detail from the very start.

⁸⁰ See Terry McGovern interview, 20-23; Maxine Wolfe interview, 83-85; “Women with AIDS demand rights,” *Workers World*, 9 April 1992. The American Medical Association was one of a number of high-profile professional bodies to support the lawsuit.

⁸¹ Maxine Wolfe interview, 87-89.

⁸² “Women don’t have AIDS, they just die from it,” information packet, November 1990, Women and AIDS Papers, Stonewall Library, Box 1.

⁸³ “CDC AIDS Definition and Women,” briefing document by Public Health Service of HHS, November 1990, GMHC Papers, New York Public Library, Box 21, AIDS and Women file.

The assertion of “no scientific evidence” was an exaggeration at best: see, for example, Chu et al, “Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of

Reproductive Age in the United States,” *Journal of the American Medical Association*, 11 July 1990, 225-229.

⁸⁴ Memo from David Hansell of GMHC, 17 March 1991, re meeting with Dr William Roper at CDC, GMHC Papers, Box 66, CDC file.

⁸⁵ ACT UP report “Women don’t have AIDS, they just die from it,” 4-5.

⁸⁶ Memo, Tim Sweeney of GMHC to management team, 5 February 1991, re Women and AIDS, GMHC Papers, Box 72, Women and AIDS file.

⁸⁷ Maxine Wolfe interview, 88-89.

⁸⁸ “Critical issues and background information,” Center for Women’s Policy Studies, Women and AIDS Papers, 1 folder. The 1991 bill was sponsored by Robert Matsui (D-CA).

⁸⁹ See Tamar Carroll, *Mobilizing New York*, chapter 6.

⁹⁰ “Women with AIDS Demand Rights,” *Workers’ World*, 9 April 1992, Stonewall Library.

⁹¹ Statement of William J Foreman of NAPWA to House Subcommittee on Social Security and Human Resources, 2 April 1992, People with AIDS Coalition Records, Box 9, NAPWA 1992-1993 file.

⁹² Gregory Kaladjian to Gwendolyn King, 14 February 1992, David Rogers Papers, Box 21, AIDS Advisory Council 3/5/92 file.

⁹³ Kaldjian to King, 14 February 1992, David Rogers Papers, Box 21, AIDS Advisory

Council file.

⁹⁴ See memoranda and draft letter from National Commission Chairs to Gwendolyn King, 31

January 1992, Rogers Papers, Box 20, Correspondence 1992 file; Roy Widdus, Executive

Director, National Commission on AIDS, to Susan Parker, Associate Commissioner on

Disability, SSA, 21 February 1992, Rogers Papers, Box 20, National Commission on AIDS

letters 1989-93 file.

⁹⁵ Statement of William J Foreman, 2 April 1992.

⁹⁶ See William J. Novak, "The myth of the 'weak' American state," *American Historical*

Review, 113:3 (June 2008), 752-772.

⁹⁷ ACT UP Background Briefing Paper, "The Insurance Industry and AIDS," ACT UP

Golden Gate Papers, UCSF Special Collections, Box 1, AIDS conference press releases and

topic sheets file.