# Between Private and Public: AIDS, Health Care Capitalism, and the Politics of Respectability in 80s America

**Abstract:** The AIDS crisis in the US in the 1980s radically transformed the relationship between sexual minorities and capitalism. Opportunistic infections given free rein in human bodies by HIV rendered employees visible to employers and to health care providers as an economic risk, and set the stage for battles between health capitalists, politicians, and AIDS activists over access to health care. Health capitalism in eighties America was both an arena of integration of queer Americans into mainstream society and also a political cul-de-sac, blunting the radical possibilities of sexual politics that were alive in the years before the AIDS crisis.

In this article I focus on activist groups, primarily ACT UP, Gay Men's Health Crisis, National Gay Rights Advocates, and National Gay and Lesbian Task Force, and the liberal politicians who led legislative battles at federal and state level to force the health care system to respond to AIDS. In shifting our gaze from the Reagan administration and the religious right as the primary foils to AIDS activism, we can gain new insights into the direction of liberal politics in an era of supposed conservative ascendancy. An understanding of how AIDS activists and their allies negotiated questions of health access suggests health care activism was in part a marker of class privilege, as gay activists and liberal Democrats openly embraced a medical model for sexual minorities that lifted them above the stigma of a public welfare system and integrated them further into heteronormative capitalism.

In April 1986, Mark Senak, the Legal Services Director of Gay Men's Health Crisis, wrote to the New York State superintendent of insurance to solicit the help of the State government. "The GMHC Legal Services Department offers legal assistance to our clients in several areas, among them in obtaining their [health] insurance benefits," he wrote. "We have noticed an ever increasing number of instances where the client is not able to get his claims paid based on an assertion by the insurance company that his condition is a pre-existing condition, [or] that he made a material misrepresentation….we have seen several clients fall into a state of helplessness." Senak asked the superintendent to assist GMHC in investigating cases of insurance companies denying health care claims of people with AIDS (PWAs), bringing the power of the state to bear on those companies that proved unresponsive to

GMHC appeals. Far from demanding government action in the realm of health care for those with what would become known as HIV, Senak framed his request as a way of lessening the impact of the AIDS crisis on the welfare system. Every insurance claim not paid meant "one more person…added to the Medicaid roles [sic] and private insurers have once again shifted their burden from the private sector to the public sector….Your cooperation…will lend considerable assistance to a person afflicted with AIDS, and will result in a saving of tax dollars to the public." Senak argued that New York's huge and ever growing AIDS caseload meant that New York State had "an obligation, both *moral* and fiscal, to ensure that those stricken with AIDS are not automatically going to have to go onto Medicaid because their insurance companies refuse to pay on groundless bases."[1]

Senak's exhortation to the state to protect his client base – gay men – from exposure to the public welfare system marked an important moment in the history of gay rights politics. Opportunistic infections given free rein in human bodies by HIV rendered employees visible to employers and to health care providers as an economic risk, and set the stage for battles between health capitalists, politicians, and AIDS activists over the social rights of sexual minorities at a time when an already enfeebled welfare state came under sustained attack in the 1980s. In this context, access to the private health marketplace became a crucible of identity formation for many gay rights activists, an essential marker of political citizenship in a nation in which public welfare was especially ill-equipped to meet their health needs. Health capitalism in eighties America was both an arena of integration of queer Americans into mainstream society, and also a constraining force, blunting the radical possibilities of sexual politics that were alive in the years before the AIDS crisis.

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[1] Mark Senak to James Corcoran, 22 Apr. 1986, Gay Men's Health Crisis Papers, New York Public Library, Box 48, insurance issues 1985-86 file. Emphasis mine.

In this article I chart the ways in which AIDS and gay rights activists, sympathetic politicians at federal and state levels, and health care providers negotiated access to the health system for PWAs. My focus is on the relationship between people now marked by a highly stigmatized disease and a private health system determined to minimize its financial liability. AIDS activists had little choice but to challenge the discriminatory practices of health insurance companies and employers. The other options open to them, principally the Medicaid and Medicare programs accessed through a poorly resourced welfare system, excluded many PWAs, and the benefits awarded were too meagre to guarantee treatment outside hard-pressed county hospitals.[2] There was also little prospect in the so-called "Reagan era" of a revolution in health care provision, despite the regular appeals for a single payer scheme during the AIDS crisis.

Yet the paucity of options open to those bearing the brunt of discriminatory employment and health policy in the 1980s disguises a separate force at work shaping the politics of AIDS activism. Many of those campaigning for access to the private marketplace in health care in the 1980s framed their appeals for inclusion as a right stemming from the claims of sexual minorities to be equal citizens in a post-Stonewall world. Gay rights advocates in the 1970s had built networks and organizations, including the National Gay Task Force and Gay Activists Alliance, which explicitly sought to secure better political representation for sexual minorities in both public and private realms. The NGTF had managed to gain access to the Carter White House to lobby for civil service and immigration reforms that would remove some of the legal obstacles to equal rights for queer Americans.[3]

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[2] See Jonathan Bell, "Rethinking the 'Straight State': Welfare Politics, Health Care, and Public Policy in the Shadow of AIDS," *Journal of American History*, 104:4 (March 2018).

[3] Claire Bond Potter, 'Paths to Political Citizenship: Gay Rights, Feminism, and the Carter Presidency," *Journal of Policy History* 24:1 (2012), 95-114; William B. Turner, 'Lesbian/Gay Rights and Immigration Policy: Lobbying to End the Medical Model,' *Journal of Policy History* 7:2 (1995), 208-225; Margot Canaday, *The Straight State: Sexuality and Citizenship in Twentieth-Century America* (Princeton University Press, 2009), chapter 6.

Gay rights groups at the local level forged links with city governments, responded robustly to political attacks, and developed gay businesses as part of a process of community formation and the development of political muscle.[4] The AIDS crisis made urgent an aspect of this drive for respectability and inclusion already apparent in the emergence of gay and women's health clinics in local communities in the 1970s: the relationship between sexual dissidence and access to health care.[5] In the context of the distinctive way in which health care was structured in the United States, many gay rights advocates saw private health insurance as a badge of their status as citizens, and were wary of the social stigma attached to the welfare state. Those in Congress and the States supportive of efforts to restrict the ability of health providers to banish PWAs from the protective embrace of private capitalism likewise balanced the necessity of engaging with the existing system with a broader commitment to it as a primary marker of social inclusion.

The 1980s represented a critical period in the evolving relationship between identity politics and capitalism. Sexual minorities, made visible as employees and stakeholders in the economy by AIDS, fought for economic rights following the same script written when the modern health care system was established after World War Two. In the late 1940s labor unions, unable to secure health security through the state, joined employers in constructing a private health insurance regime protecting employees and their dependents.[6] The main

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[4] Elizabeth Armstrong, *Forging Gay Identities: Organizing Sexuality in San Francisco, 1950-1994* (Chicago: University of Chicago Press, 2002); Timothy Stewart-Winter, *Queer Clout: Chicago and the Rise of Gay Politics* (Philadelphia: University of Pennsylvania Press, 2016).

[5] Katherine Batza, *Before AIDS: Gay Health Politics in the 1970s* (Philadelphia: University of Pennsylvania Press, 2018).

[6] Michael K. Brown, 'Bargaining for Social Rights: Unions and the Re-emergence of Welfare Capitalism,' *Political Science Quarterly*, 112:4 (Winter 1997-1998): 645-674; Jennifer Klein, 'The Business of Health Security: Employee Health Benefits, Commercial Insurers, and the Reconstruction of Welfare Capitalism, 1945-1960,'*International Labor and Working Class History*, 58 (Fall 2000), 293-313; Nelson Lichtenstein, 'From Corporatism to Collective Bargaining: Organized Labor and the Eclipse of Social Democracy in the Postwar Era', in *The Rise and Fall of the New Deal Order, 1930-1980*, ed. Steve Fraser & Gary Gerstle (Princeton: Princeton University Press, 1989).

innovation in government-provided health care in the post-war era, Medicare, also privileged wage-earning as the gateway to coverage through Social Security taxes. Non-contributory government programs developed in these years were limited to special categories of Americans, including veterans, the needy aged, disabled, and families with dependent children, categories assumed to be heteronormative.[7] Many queer Americans also accessed the new private health marketplace in the postwar era, but as workers whose sexuality had to remain hidden to avoid the threat of unemployment if discovered. Steady employment and its associated fringe benefits, including health care, became as much a marker of economic citizenship for gay men and women as for straights, even if overshadowed by far more pressing political concerns related to the civil rights needs of sexual minorities.

The AIDS crisis rendered visible this previously obscured economic facet of the rights revolutions of the Sixties: gay employees were now classed by employers and health insurance companies not only as an identifiable category of people, but one with a particular health risk attached to it. In their complex struggle to master the arcane details of the US health care system and prevent people with AIDS (or at least those privileged enough to experience private health coverage) from becoming classed as uninsurable and cut off from access to care, AIDS activists and their political allies had to confront their previously unspoken reliance upon a system that had now turned on them. In their efforts to preserve access to health insurance, activists adopted a language of entitlement that associated private health capitalism with respectability and citizenship. They did so just as the private system was in crisis and coverage was dwindling, a result of a broader economic trends that marked the end of a golden era of corporate welfareism of the post-war decades. The AIDS crisis struck at the very moment neoliberal notions of governance were gaining significant traction

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[7] As Margot Canaday has shown, the GI Bill of 1944 explicitly excluded servicemen given dishonourable discharges, including those accused of having same-sex relationships. Canaday, 'Building a Straight State: Sexuality and Social Citizenship under the 1944 GI Bill,' *Journal of American History,* December 2003, 935-957.

in American politics, leading to the scaling back of both public and private routes to social welfare and tying the maintenance of good health ever more closely to private wealth rather than to collective agreements between management and workers.[8] The association of full economic citizenship with a privatized health marketplace thus became even more necessary just at the point gay rights campaigners joined the health care debate as sexual subjects. Corporate responses to AIDS were driven as much by these economic realities as by homophobia. The head of the Washington Business Group on Health told a meeting of health insurers in 1987 that a crisis in health care financing was having the ironic effect of placing private insurers in the position of expecting more government involvement in the system – "you want national risk control insurance" – while liberal Democrats and AIDS activists led the fight to retain access to the private market.[9]

In this article I focus on activist groups, primarily ACT UP, Gay Men's Health Crisis, National Gay Rights Advocates, and National Gay and Lesbian Task Force, and the politicians, primarily Democrats from New York and California, who led legislative battles at the federal and state levels to force the health care system to respond to AIDS. In shifting our gaze from the Reagan administration and the religious right as the primary foils to AIDS activism, a narrative that dominates the historical literature and yet did not have as much of a legislative legacy on AIDS policy as Democrats in the 1980s, we can gain new insights into the direction of liberal politics in an era of supposed conservative ascendancy. While much important scholarship has been written from the top down about presidential politics in the 1980s, and some work has been done by historians working on the intersections between domestic activism and international politics, not enough attention has been paid to the impact

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[8] See David Harvey, *A Brief History of Neoliberalism* (Oxford: Oxford University Press, 2005); Angus Burgin, *The Great Persuasion: Reinventing Free Markets Since the Depression* (Cambridge, Mass.: Harvard University Press, 2012); Daniel Rodgers, *Age of Fracture* (Cambridge, Mass.: Harvard University Press, 2012).

[9] "Health insurers face a number of challenges," *National Underwriter*, 28 Sept. 1987, 18.

of Reagan-era liberals on domestic social policy.[10] By paying close attention to these debates in the context of the AIDS crisis, and by focusing attention on a range of figures from both inside and outside the public policy mainstream, this article highlights the deep entanglements between liberal and conservative approaches to public policy in a period too often characterized as one of near-total conservative dominance. In addition, in making health capitalism a key driver of political responses to AIDS, we add to our understanding of queer Americans as class-conscious consumers in a post-civil rights era.[11] A focus on health care access as a form of activism also encourages us to expand our definition of queer activist politics in the 1980s beyond a civil rights and drug research paradigm and to see more clearly the links between sexuality, class, and capitalism.[12] Finally, an understanding of how AIDS activists and their allies negotiated questions of health access provides texture and context to what onetime Director of the NGLTF Urvashi Vaid has termed the "mainstreaming" and

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[10] General histories of the 1980s all focus on AIDS activism in the context of Reagan-era conservatism: see Doug Rossinow, *The Reagan Era: A History of the 1980s* (New York, Oxford University Press, 2015), 129-34, 212-15; James T. Patterson, *Restless Giant: The United States from Watergate to Bush v Gore* (New York: Oxford University Press, 2007), 179-182; Sean Wilentz, *The Age of Reagan: A History, 1974-2008* (New York: Harper Collins, 2008), 185-6. More specialist treatments also place a hostile administration at the heart of political responses to AIDS: see William B. Turner, 'Mirror Images: Lesbian/Gay Civil Rights in the Carter and Reagan Administrations,' in John D'Emilio, William B. Turner, and Urvashi Vaid, eds., *Creating Change: Sexuality, Public Policy, and Civil Rights* (New York: St. Martin's Press, 2000): 3-28; Turner, 'Adolph Reagan?: Ronald Reagan, AIDS, and Lesbian/Gay Civil Rights,' *Social Science Research Network*, 2009: available here:http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1433567; Jennifer Brier, *Infectious Ideas: US Political Responses to the AIDS Crisis* (Chapel Hill: University of North Carolina Press, 2009), especially chapter 3. For discussions of international activist politics in the 1980s, see Bradford Martin, *The Other Eighties: A Secret History of America in the Age of Reagan* (New York: Hill and Wang, 2011); Nick Witham, *The Cultural Left and the Reagan Era: US Protest and Central American Revolution* (London: I B Taurus, 2015); Brier, *Infectious Ideas*, chapter 4.

[11] See Peter F. Cohen, 'All They Needed: AIDS, Consumption, and the Politics of Class,' *Journal of the History of Sexuality*, Vol. 8, No. 1 (Jul., 1997), pp. 86-115; Jeffrey Escoffier, 'The political economy of the closet: Toward an economic history of gay and lesbian life before Stonewall,' in Escoffier, *American Homo: Community and Perversity* (Berkeley: University of California Press, 1998), 65-78; Timothy Stewart-Winter, *Queer Clout: Chicago and the Rise of Gay Politics* (Philadelphia: University of Pennsylvania Press, 2016).

[12] There is a huge literature on AIDS activism, much of it framed in terms of activist battles against discrimination on the part of the state or political inattention to the civil rights and treatment needs of sexual minorities. See David France, *How to Survive a Plague: The Inside Story of How Citizens and Science Tamed AIDS* (New York: Knopf, 2016); Deborah Gould, *Moving Politics: Emotion and ACT UP's Fight Against AIDS* (Chicago: University of Chicago Press, 2009); Sean Strub, *Body Counts: A Memoir of Activism, Sex, and Survival* (New York: Scribner, 2014); Anthony Petro, *After the Wrath of God: AIDS, Sexuality, and American Religion* (New York: Oxford University Press, 2015).

"degaying" of the AIDS crisis to make it more politically palatable to a wider population, a strategy that "depoliticized it as a movement."[13] This argument is in many ways accurate, but "degaying" was not simply a product of activist weakness in the face of virulent homophobia, but also a marker of class privilege, in which gay activists and liberal Democrats openly embraced for sexual minorities a medical model that lifted them above the stigma of a public welfare system and integrated them further into heteronormative capitalism.

## The Eighties Health Care Crisis and the Making of Queer Subjects

AIDS arrived as a major health crisis at the very time the private health system was seeking to limit its liabilities and constrain costs. Double-digit medical cost inflation since the 1960s had made it ever harder for companies to cover every medical eventuality, and employees were facing a larger share of their medical bills and a larger number of excluded conditions or denied claims even before AIDS threatened to expose the underlying frailties in the pattern of health care delivery.[14] The AIDS epidemic sent insurers into paroxysms of anxiety. "AIDS is an epidemic of uncertain proportions and characterized, it is believed, by the consumption of unusually high levels of health care," wrote policy experts Gerald Oppenheimer and Robert Padgug in 1987. "To make matters worse, AIDs and ARC mainly strike males between the ages of twenty and fifty, precisely the classes that are most commonly found in employee health insurance groups…and that, until now, have had the lowest rates of health care utilization. AIDS seems to strike directly at the heart of the principles of 'sound underwriting' that underlie private health insurance."[15] As the medical

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[13] Urvashi Vaid, *Virtual Equality: The Mainstreaming of Gay and Lesbian Liberation* (New York: Random House, 1995), 74-78.

[14] Beatrix Hoffman, *Health Care for Some: Rights and Rationing in the United States since 1930* (Chicago: University of Chicago Press, 2012), chapter 8; Howard E Freeman et al, 'Americans report on their access to health care,' *Health Affairs* 6:1 (Spring 1987).

[15] Gerald M. Oppenheimer and Robert A. Padgug, "AIDS and Health Insurance: Social and Ethical Issues," *AIDS and Public Policy Journal*, vol. 2, Winter 1987. The term "ARC" means "AIDS-related condition" a 1980s term for HIV-related conditions that the Centers for Disease Control had not categorized as AIDS.

director of one insurance company put it, the low life expectancy rates of a person with AIDS meant that "[a]ctuarially, he's the same as a 75-year old man."[16] Employers and insurance companies quickly began finding ways to limit their liability for a syndrome no one yet understood. In so doing, they quickly made health care a major political issue for gay rights activists, as gay men were easily the largest affected population who also possessed health insurance in any numbers.

There were three principal routes to denying access to private health benefits to those who were what we now term HIV-positive, or even to those merely suspected of being at risk of the disease. The simplest was to dismiss employees from their jobs, either on the basis of their sexuality alone or because an AIDS-related illness made them unable to work. One gay male patient, an advertising executive, in a New York hospital in 1987 revealed the dynamics of a new closet enveloping gay men during the epidemic, made real by their status as employees desperate to retain a route to health care. While in hospital "we lost one of the accounts that I was working on. For the first time in my career I was confronted with the insecurity of my job. I realized that at that point in my life the most important thing for me is that I continue to have my insurance, my medical coverage….So, to protect myself, I felt that I had to go on a medical leave-of-absence to insure I wouldn't be laid off and left without insurance…" He never told his company he had AIDS, instead naming specific conditions for which he was seeking treatment, and assumed many HR departments would not make the connection.[17] Hiding HIV-antibody status became a new closet in a health economy in which access to insured employment was a gateway to care. And in some companies, sexuality itself

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[16] "AIDS cost could lead to national insurance plan," *National Underwriter*, 9 Nov. 1987.

[17] AIDS – Interview with AIDS patient, April 1987, in David Rogers papers, New York Hospital, Weill-Cornell Medical Center, Archives, Box 19, AIDS files.

remained a wider point of contention, as they fired employees suspected of being gay irrespective of HIV status.[18]

A second common practice, one that made even more explicit the relationship between sexuality and political economy in this period, was that of "redlining", an effort on the part of insurance companies to identify at-risk populations and exclude them from coverage. Although large group policies usually provided space for gay men to hide from the attentions of underwriters, small employers and individuals trying to procure insurance faced a more challenging environment in the 1980s. A survey of small business health policies found that hair salons, for example, were described as "a 'triple threat' – high employee turnover with little interest in long-term employment, a high proportion of women of child-bearing age, and a high proportion of homosexual men. Bars, taverns, and liquor stores, considered ineligible by ten of the plans [surveyed], are perceived as bad risks because of high employee turnover and hazardous or unhealthy working conditions." Many small business and individual policies excluded certain medical conditions from coverage.[19]

Individuals, many of them scrabbling for coverage after losing their group employment plans, faced an even tougher time. An interoffice memorandum from one insurance company in 1985 set out various "non-medical" factors that could deny an individual life or health insurance, including anyone who was a single adult between 20 and 50, those displaying a "sexually promiscuous or illicit lifestyle," or who lived in particular cities associated with AIDS. The document also listed medical conditions commonly associated with HIV, and urged assessors to evaluate "very carefully whether there is any

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[18] For an example, see "Company ousts gay workers, then reconsiders," *New York Times*, 28 Feb. 1991, http://www.nytimes.com/1991/02/28/us/company-ousts-gay-workers-then-reconsiders.html concerning homophobic discrimination at Cracker Barrel.

[19] Wendy Zellers, Catherine McLoughlin, Kevin Fisher, "Small business health insurance: Only the healthy need apply," *Health Affairs*, Spring 1992, 174-180. Gay bars would come under particular scrutiny by insurance companies. The insurance industry seemed not to notice the racist lineage of the term 'redlining.'

indication of venereal disease….If the condition is present or less than five years in history, consider declining." The document effectively drew a portrait of the gay male as economic risk, concluding that the "various medical and nonmedical factors enumerated, while generally not indicative if found alone, point to a high probability of AIDS exposure when several are found together…as underwriters we must do our best to avoid accepting such risks."[20] A member of the New York State Assembly complained to the state insurance regulator that he had learned that "some companies would hire outside agencies to run background checks on applicants. They would interview neighbors, investigate whether the applicant lives with another man, etc. It was even suggested that investigators would check the names on mail boxes to see whether the applicant lives with another man. Essentially the company would try to weed out applicants who are perceived to be gay males and deny them health and life insurance coverage."[21]

The third tactic employed by insurance companies and employers involved changing the rules of the game for those already enrolled in a group policy, either by imposing new limitations on what employees could claim, changing the terms and conditions of the policy, or even threatening to terminate the policy altogether. Employers could also decide suddenly to change provider to cut costs, often accepting a less favorable benefits package and a new round of underwriting investigations into employees. Ever more employers were also choosing to self-insure their employees, keeping employee contributions and paying medical costs out of their own pockets, but able to decide on a case-by-case basis what – as well as whom - to cover and to exclude. A loophole in the law governing state regulation of the insurance industry excluded self-insured companies from government oversight of their

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[20] Interoffice memorandum, MARC-Life Company, 23 Sept. 1985, "Underwriting guidelines for AIDS", Stan Hadden papers, GLBT Historical Society, San Francisco, Box 7, insurance '85 file.

[21] Jerrold Nadler (D-NY) to James Corcoran, 26 Aug. 1985, GMHC papers, New York Public Library, Box 48, insurance issues 1985-86 file.

insurance provisions. In 1988, Circle K, the country's second largest convenience store chain, suddenly announced to 8,000 insured employees, roughly a third of the total workforce, that it would exclude from coverage all sexually or IV-drug-transmitted AIDS, alcohol or drug abuse, or other "self-inflicted wounds," arguing that "personal lifestyle decisions" of some employees "could seriously impact other participants' health care costs."[22] In cases where companies did not self-insure and so could not always discriminate so openly (some states banned insurers from refusing to cover AIDS), there was the option of picking a provider that imposed limits on AIDS claims. Joel Starkey, an HIV-positive landscape and maintenance supervisor in Boca Raton, Florida, suddenly found himself enrolled in a new plan that imposed a $5000 annual and $15000 lifetime limit on reimbursement for AIDS treatment, pitifully small sums insufficient to cover even one hospital stay.[23] When Starkey involved the National Gay Rights Advocates and threatened to sue the insurance company, a representative visited his workplace and told him in front of his boss that they would cancel the health plan for the entire workforce if the lawsuit went ahead.[24] In this context, a strategy to retain access for people with AIDS to a health care system poorly equipped to serve them became a central focus for gay rights activists and their small band of supporters in legislatures.

## "We are not yet Detroit": AIDS politics and the stigma of welfare

By the end of the 1980s, around forty percent of people with AIDS were on Medicaid, a program that comprised roughly 25% of all AIDS-related personal health care costs in the

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[22] "The Circle K Affair," *New York Native*, 5 Sept. 1988. The battle for health coverage had a class dimension, as not all Circle K employees were able to afford the company's health plan in the first place. See also "Company halting health plan on some 'lifestyle' illnesses", *New York Times*, 6 Aug. 1988, accessed at http://www.nytimes.com/1988/08/06/us/company-halting-health-plan-on-some-life-style-illnesses.html (accessed 23 Nov. 2017).

[23] Starkey statement, nd, Starkey papers, Stonewall Library, Fort Lauderdale, Florida, AIDS discrimination box 1 of 2.

[24] Starkey to Ben Schatz of NGRA, 23 Nov. 1987, Starkey papers, AIDS discrimination box 2 of 2, AIDS discrimination lawsuit – NGRA file.

United States.[25] It was inevitable that the public health system would come under intense pressure as more and more PWAs lost their health insurance, not to mention the fact that many had never had private coverage in the first place. It was also unsurprising that the AIDS crisis ignited calls for universal health care. Yet the American welfare state was singularly unsuited to deal with a public health disaster of these proportions. It was impossible to qualify for Medicaid coverage without first qualifying for a welfare program, the only one of which covered most men or anyone without children being Supplementary Security Income (SSI). In order to claim SSI applicants had to be classed as disabled by the Social Security Administration, a process that was not straightforward and excluded many HIV-positive people who did not fit the rigid and inflexible government definition.[26] The same restrictions applied to Medicare, with the added complication that claimants of Social Security Disability Insurance – who first had to have paid social security taxes for the requisite number of years – had to wait two years after qualifying as disabled to claim Medicare benefits. Most PWAs had died before they could qualify for Medicare. Many health care providers did not accept Medicaid because states often offered meagre rates of reimbursement, and also limited how much claimants could use particular services.[27] And with a Republican in the White House and liberals on the defensive in Congress, there was no prospect of any improvement in the welfare system; if anything, congressional guardians of the Social Security system were fighting a rear guard action to prevent further cuts.

The main factor driving AIDS treatment activism into a desperate and deeply antagonistic embrace of private health capitalism as the crisis deepened was not simply the inadequacy of the welfare state. The concentration of an escalating AIDS caseload in a

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[25] William Winkelwerder et al, "Federal spending for illness caused by the Human Immunodeficiency Virus," *New England Journal of Medicine*, 15 June 1989, 1598-1603.

[26] See Jonathan Bell, "Rethinking the Straight State."

[27] Anthony Pascal et al, "State policies and the financing of Acquired Immunodeficiency Syndrome care," *Health Care Financing Review*, Fall 1989, 91-103.

handful of urban centers, together with the growing reliance of PWAs on underfunded and overstretched public hospitals, threatened to bring the health systems of those cities – New York in particular - to the brink of collapse. Politicians from those cities at the vanguard of AIDS policymaking shared with gay rights groups the concern that a large population of middle class gay men would be dumped into a public welfare system branded by social stigma and inimical to efforts to integrate sexual minorities into mainstream American life. Debates over how best to respond to AIDS reified the private sector as the respectable face of citizenship, and cast the public option as the preserve of the socially marginalized: a social policy problem thus had an ideological dimension. The fact that private health interests and Reagan administration officials were keen to encourage the transfer of AIDS patients to the woefully inadequate welfare system and continue to underfund it clearly demonstrates the flipside of this ideological coin, consigning sexual dissidence to the fringes of social citizenship. "A chilling thought," wrote Reagan domestic policy advisor Tom Gibson to Pat Buchanan in October 1985. "If you follow the recent trends of anti-redlining and insurance non-discrimination case law to their logical conclusion with AIDS, in a matter of years we could be faced with 'no fault medical/life insurance' laws. That's when I move to Australia."[28] For liberals, by contrast, the private sector offered a way of protecting the crisis-plagued welfare system from collapse while also mainstreaming the gay civil rights movement.

Regular testimony from those at the coalface of the unfolding public health crisis in the 1980s served to underline the unfortunate class and racial cross-currents shaping the political antipathy to state-centered solutions. Doctors, hospital directors, activists, and politicians repeatedly bemoaned the catastrophic inadequacy of emergency rooms and charity

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[28] Tom Gibson to Pat Buchanan, 18 October 1985, Ronald Reagan papers, Reagan Presidential Library, Simi Valley, HE001 subject file 3499533.

clinics struggling to tackle a mounting caseload. “We are not yet Detroit,” wrote New York AIDS specialist David Rogers, “but I think there’s everything to suggest that we are moving swiftly in that direction. It’s not just AIDS – it’s poverty, it’s violence, it’s drugs, it’s teenage pregnancies, and on and on and on that will, I believe, make New York City decline and fall like the Roman Empire.”[29] Speaking of his hospital’s emergency room, Dario Gonzalez of Queen’s General Hospital reported of a facility “bursting at the seams, just waiting for a disaster.”[30] New York City Health Commissioner Stephen Joseph told an AIDS conference that “AIDS and HIV-related sickness and death in IV drug users, their sex partners, and children are battering the city’s poor and minority residents. The highest case rates, especially outside Manhattan, are most often in the poorest socio-economic areas,” pointing to “the increasing involvement of blacks and Hispanics. Indeed, in New York City the AIDS epidemic is not one epidemic, but a group of overlapping epidemics affecting different groups.”[31] City mayors like Ed Koch of New York begged Congress for more direct funds to shore up crumbling public hospitals.[32] Their vivid portraits of AIDS as a crisis of drug abuse, poverty, racism, and a weak and impoverished public health system demonstrated clearly the wider significance of the disease, but left unspoken how affected populations not historically associated with the urban underclass would be integrated into this narrative. The dominant language of gay rights was one of empowerment and social acceptance, not of poverty and exclusion.

Gay rights groups were quick to mobilize in order to an effort to minimize their association with a rapidly declining public health system. Gay Men’s Health Crisis, formed in

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[29] David Rogers to Jeremiah Beronders of New York Academy of Medicine, 30 Nov. 1990, Rogers papers, Box 23, AIDS miscellaneous file.

[30] “New York health care failure charged,” *New York Times*, 8 Dec. 1988.

[31] Remarks of Stephen Joseph to the fifth international conference on AIDS, 5 June 1989, Steve Morin papers, GLBT Historical Society, Box 1, folder 1.

[32] See Koch to Daniel Patrick Moynihan, 23 Sept. 1986, Moynihan papers, Library of Congress, Box 1712, folder 1.

1982 right at the start of the epidemic, was a perfect example of the lobbying power at the disposal of the primarily white gay male client group. It had an Office of the Ombudsman, which handled some 150 complaints monthly about the delivery of health services, and which actively lobbied health providers and the city and state government in New York.[33] It employed welfare counsellors to help People with AIDS put together applications for SSI and Medicaid. Its directors gained access to policymakers at the Centers for Disease Control and Social Security Administration. Likewise, the National Gay Task Force had been able to secure meetings with the Carter White House in 1977, and in 1986 moved its ever-expanding operation to Washington to be closer to Capitol Hill. The number of LGBT lobbying organizations proliferated in the 1980s.[34] The lobbying efforts of these various organizations ranged widely, including over federal government research funding, the FDA drug approval process, and access to welfare. Crucial, however, for many people with AIDS was the effort to retain access to private health care. As one member of GMHC argued to the director of CDC in January 1986, failure to do so would shift "the burden of [PWAs'] health care…from the private sector to the federal, state, and city governments, i.e. to the taxpayer. It does not take much effort at mathematics to understand that this would strain the Medicaid system beyond the limits of its endurance." He warned of the ruinous financial consequences of GMHC clients becoming "charges of the State as a result of their uninsurability."[35] Ironically, as we shall see, efforts to privatize the health needs of LGBT people in the eighties required a significant involvement of the state, and close collaboration with a liberal politics struggling to define its mission in an age of conservative ascendancy.

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[33] Testimony of Catherine Daley, Director of the Office of Ombudsman, GMHC, to New York City Department of Health, 2 May 1989, GMHC papers, New York Public Library, Box 46, health and hospitals corporation NYC file.

[34] See Claire Bond Potter, "Paths to political citizenship: Gay rights, feminism, and the Carter Presidency," *Journal of Policy History* 24:1 (January 2012), 95-114; Urvashi Vaid, *Virtual Equality*, 74.

[35] Mark Senak, Legal Services director GMHC, to James Curran, CDC, 16 Jan. 1986, GMHC papers, Box 48, insurance issues file.

## Public policy, private health: the state, employers, and the right to care

For those in Congress who shared the concern of the GMHC that the erosion of the private health marketplace would expose the fragile welfare system to unbearable new pressures, an opportunity came in 1985 to slip an important but little remarked upon policy into that year's Consolidated Budget Reconciliation Act (COBRA). Mindful of the growing number of Americans losing health insurance, especially when leaving or moving jobs, a House-Senate committee approved a measure mandating the continuation of health insurance benefits for certain categories of people at risk of surrendering their coverage. At its heart, the statute was resolutely heteronormative, offering 36 months of continuous insurance to surviving spouses and children of deceased employees, as well as to those separated or divorced from covered employees and to children about to lose their parents' coverage. Yet it also mandated eighteen months of additional cover to anyone losing their job, either due to redundancy or resignation.[36] Qualified applicants would have to pay the premiums as normal, but would continue to receive group health benefits they would never be able to afford if forced to apply for coverage as an individual. The measure quickly became a lifeline for PWAs forced out of employment and at risk of finding themselves at the mercy of the ramshackle welfare system or charity care. A GMHC leaflet advising PWAs of their legal rights, including under COBRA, underlined the importance of the role of insurance as the new frontier of gay civil rights: "your insurance may be the most important thing you have, and it is extremely important to keep it up."[37] A few years later, liberals in Congress, led by Henry Waxman (D-California) and Senator Daniel Patrick Moynihan (D-New York) and strongly backed by GMHC, attempted to reform Medicaid to allow states to use federal

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[36] Summary of COBRA 1985 continuation of health insurance provisions, Starkey papers, AIDS discrimination box 1 of 2, legal information file.

[37] GMHC leaflet "Legal answers about AIDS: Questions and Answers about the legal aspects of Acquired Immune Deficiency Syndrome," Starkey papers, AIDS discrimination box 1 of 2, AIDS discrimination lawsuit – legal information file.

matched funding to pay COBRA coverage for PWAs. The rationale was that it would be “less expensive than allowing such insurance coverage to lapse and forcing Medicaid to pay health care and medical bills. This provision would also help slow the process of private insurers shifting the cost of AIDS care onto public programs.”[38] The plan said nothing about those not covered by group insurance in the first place, whose voices went unheard in the meetings and correspondence between gay rights groups and legislators in Washington.

The new law sparked a wave of “mini-COBRAS” at the state level. States either extended COBRA benefits to small employers (the federal law only applied to employers of more than twenty staff), or lengthened the qualifying period beyond the federal limit. Thirty-one states provided these extended benefits by 1988, and some also banned insurers from using HIV status to exclude pre-existing conditions or to cap certain treatments or services. California, Georgia, Kansas, North Carolina, and Pennsylvania did all three. A few states also prevented insurers from questioning applicants about their HIV status, or from denying coverage on the basis of a person’s sexuality.[39] As more and more Americans lost their health insurance in the 1980s, a product of spiralling health care costs, deindustrialization, weak labor laws in many states, as well as the AIDS crisis, it fell to governments to prop up an ailing system so that they could safely ignore the chronically underfunded, overstretched Medicaid program. As the sun set on a golden era in which private employers formed the lynchpin of the middle class welfare regime, those with a precarious purchase on health insurance – including those with HIV – found themselves in a liminal space between the private and public realms.

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[38] Summary of Medicaid AIDS and HIV amendment of 1990, Daniel Patrick Moynihan papers, Box 1711, folder 3. See also memo in same from Curtis Kelly to DPM, 3 Apr. 1990, re meeting with GMHC representatives to discuss the bill.

[39] Anthony Pascal et al, “State policies and the financing of Acquired Immunodeficiency Syndrome care,” *Health Care Financing Review*, 11:1 (Fall 1989), 91-103.

That this no man's land between public and private still required an ideological as well as rhetorical commitment to capitalism as the key to social legitimacy for the sick is clearly shown if we examine efforts at the state level to create yet further government involvement in the health insurance industry by establishing special risk pools for those deemed uninsurable. These risk-pool insurance plans provided state-subsidized high premium health cover for patients no longer covered by employment insurance but outside the protective umbrella of the welfare system.[40] Only a handful of states had introduced risk pools as the health insurance crisis took hold, but AIDS helped pushed the question up the political agenda in high-incidence states like California in the mid-1980s. The idea of a state-managed risk pool broke the traditional twentieth-century link between insurance and employment, and committed supporters to a much more broadly defined right to health care than the standard private model allowed.

Yet it also tended to be wheeled out as a way of preserving the distinct place of the middle-class insurance holder in society, separated from the indigent poor in public policy. The principal sponsor of a 1986 effort in California to enact a risk pool, Assemblyman Alister McAlister, acknowledged that "the yawning gaps in our health insurance system represent the great unfinished issue in Social Agenda," and yet he characterized his plan as "moderate" and a way of heading off calls for more radical restructuring. "These demands will be voiced not by the poor, who with a clear conscience can always rely on Medi-Cal, but by the middle class who in significant numbers are forced to dissipate their lifetime savings and reduce themselves to pauper status in order to qualify for Medi-Cal when afflicted by a major debilitating illness." He feared that "we are only feeding fuel to the fires of those who would overturn the existing system with an absolutely comprehensive but, regrettably, nationalized

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[40] See Moynihan to Jeffrey Carples, New York Department of Social Services, 4 Dec. 1986, Moynihan MSS, Box 1717, folder 2.

system with all of its negative implications for a healthy free enterprise economy, stultifying bureaucracy, bigger government and reduced incentives for medical professionals."[41]

When applied to Americans with HIV, the logic was that those with socio-economic backgrounds that had hitherto given access to private insurance needed to be shielded from the stigmatization of pauperism, a process designed to maintain the class and social status divisions underpinning the health care system. When the proposal finally became law and enrolled its first clients in January 1991 as the Major Risk Medical Insurance Program, a meeting called between a representative of the program and interested parties on "MRMIP/HIV Care" that month discussed "using MRMIP as a model to purchase comprehensive care for people with HIV. It would help mainstream care." This idea of "mainstreaming," of removing stigma and marginalization by stamping HIV patients with the acceptable imprimatur of health care provision – insurance – raised awkward questions about the status of those who could not afford the high premiums of MRMIP and who could not access the insurance market. MRMIP staff were aware of the issue, wondering whether California counties saddled with Medi-Cal payments to disability recipients "could conceivably shift some [late stage medical assistance] people to MRMIP? This is interesting potential for low-income people and counties with waiting lists at county clinics."[42] Yet no one had answers to how to pay the swollen premiums required when it was far easier to stick with a public assistance system that could be cut at will as required. Given the mounting budget crisis in California by the end of the 1980s, a solution to the health access problem seemed remote. "With 50,000 AIDS cases in California projected over the next five years, medical care costs could exceed $3.5 billion…The projected 50,000 cases…could result in

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[41] McAlister press release, 1 Oct. 1986, California Association of Social Workers MSS, Box 30, folder 21.

[42] Notes from meeting between Stan Hadden (State Sen.Roberti's office), Anne Powell (Assembly Health Committee), John Dunn-Mortimer (AIDS Project LA), Alan Lofaso (LIFE), and Sherry Shewry (MRMIP), 28 Jan. 1991, Stan Hadden papers, Box 1, correspondence incoming/outgoing file Jan-Sept 1991 file. Note that of the initial four thousand applications for MRMIP coverage, between one quarter and one third were HIV positive.

hospital losses totalling $180 million," stated a 1988 report of the California Association of Hospitals and Health Systems. "Neither public nor private hospital sectors are prepared to absorb this loss."[43] Surgeon General Everett Koop made explicit the ongoing link between the political economy of health care and notions of citizenship when he framed the challenge of AIDS as one of giving "the country a way of caring for AIDS patients while preventing an escalation of costs…We need to stop [AIDS] in a way that is effective yet consistent with American law and tradition."[44]

## "Let's do some market reforms": AIDS activism and the politics of the mainstream

Government efforts to harness the power of the state to discipline the private insurance marketplace did not come out of nowhere. Key policymakers, including Henry Waxman, Nancy Pelosi, Barbara Boxer, Daniel Patrick Moynihan, Ted Weiss, Ted Kennedy in Congress and legislators like David Roberti of California at the State level, all had strong ties to gay rights organizations. Groups including National Gay Rights Advocates, Gay Men's Health Crisis, National Gay and Lesbian Task Force and, from 1987, ACT UP, energized by the epidemic that was claiming so many lives, lobbied intensively. But their efforts to shape both public policy and private insurance industry responses to AIDS pointed to the conflict between the parlous position of PWAs within the health care system and the need to assert the legitimacy of gay rights activism as a mainstream issue. Middle class, mostly white leaders of gay rights organizations were reluctant to relegate themselves to the status of needy indigents in the public debate over health care access. In December 1986, for example, Jeffrey Levi of the NGLTF and Ben Schatz of the National Gay Rights Advocates

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[43] 'Health Issues in California 1988,' California Association of Hospitals and Health Systems report for CA congressional delegation, Morin papers, Box 20, folder 5.

[44] Testimony of Everett Koop, Hearings of Congressional subcommittee on Health and the Environment of the House Committee on Energy and Commerce, 19 Feb. 1988, Morin papers, Box 6, file 5.

produced a position paper to lobby the National Association of Insurance Commissioners' Advisory Committee on AIDS, a working group charged with assessing whether the actuarial risk posed by HIV infection justified a policy of antibody testing in order to deny insurance coverage. The position paper opposed the use of testing as an actuarial tool using an argument that legitimized same-sex sexuality through a presumed access to a private health care system and the wider fruits of a citizenship defined by a reliance on private, not public, welfare. Access "to health insurance is synonymous in the United States with access to quality health care," they claimed. "Any policy that might result in denial of coverage to a large group of individuals must be given especially close scrutiny." Embedding their argument in the realities of the structure of the nation's health care system, they noted that "those who test positive would be forced to depend on public welfare programs such as Medicare and Medicaid for their health care. This means the individual will be denied the same quality of care as those on private insurance plans and the public sector will have to assume a much greater financial burden." Turning a 1980s trope of government retrenchment to their cause, they noted "the existence of enormous budget deficits," making it "far more difficult for the government to assume new expenses. Indeed, while the government performs thousands of vital functions, the sole purpose of health insurance is to pay for medical expenses."[45]

In a further position paper aimed at Congress, Schatz repeated his arguments but made more explicit the class implications of the campaign for private insurance access: "If gay men become defined as uninsurable, employers will be more likely to refuse to hire them in order to avoid higher group premiums. The denial of life insurance coverage to gay men

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[45] Jeffrey Levi and Benjamin Schatz, "AIDS-related Issues and Insurance: A Position Paper," December 1986, Moynihan MSS, Box 1718, folder 2.

and others will make it difficult for them to obtain mortgages and purchase homes."[46] Omitted from his analysis was the fact that many gay men were already uninsurable thanks to the ever-growing number of jobs in the United States which did not provide insurance, or included only limited cover. The association of men who have sex with men (MSM) with the trappings of middle class consumerism and home ownership made plain the narrow angle of vision of the health care campaign of groups like the NGRA. Furthermore, NGRA's strategy, one shared by other organizations employing consulting attorneys, such as GMHC, of taking on individual employee legal actions against employers trying to revoke or restrict health care access privileged those who actually had insurance already, and further consolidated the symbiotic relationship between the gay rights movement and private employment as the vehicle of social citizenship. As in the case of other middle-class employees ever since the explosion of corporate health care provision after the 1940s, gay activists saw corporate America as an obvious target for lobbying, less labyrinthine and impenetrable than government bureaucracy, and sometimes open to change, even as it also proved easily able to cut back and restrict its health provision in response to economic circumstance.[47] Men like Joel Starkey, who waged a war of attrition with his employer for well over two years over declining coverage for AIDS, and who deployed the services of NGRA, the ACLU, and the NGLTF, were articulate, rights conscious, and often experienced in gay rights advocacy. Even then they often got nowhere with insurance companies: if the company self-insured, there was little by way of legal redress, and even if not, companies could justify changing or

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[46] Ben Schatz, Director, AIDS Civil Rights Project, NGRA, position paper on AIDS and insurance, Starkey papers, AIDS discrimination Box 1 of 2, AIDS discrimination lawsuit – legal information 1986-89 file.

[47] Larger corporations sometimes moderated their restrictive policies on AIDS as a result of political pressure, protected by their large workforces that mitigated the level of risk in insurance provision: see "Employers endorse AIDS guidelines," *New York Times*, 18 Feb. 1988. Yet they also rolled back insurance coverage during the neoliberal era of the 1980s-2000s: for an example, see Phil Tiemeyer, *Plane Queer: Labor, Sexuality, and AIDS in the History of Male Flight Attendants* (Berkeley: University of California Press, 2013), chapter 8.

eliminating coverage so long as they did so for all their employees and so did not openly discriminate.[48]

This is not to argue that grass roots activism in the face of an intransigent health insurance industry was unimportant. ACT UP's insurance committee, formed in 1989, is a case in point of how community action could make a difference in a country in which the public welfare system was never going to be adequate. The committee consisted of a mixture of committed queer activists and some industry professionals, such as Bob Padgug of Empire Blue Cross and Blue Shield and the private investment expert David Peterson, who provided insider knowledge of the system. Like many other parts of ACT UP, the insurance committee epitomized the concept of activist as self-taught expert, underscoring a degree of class privilege that in this instance led to a strategic emphasis on private insurance. Committee member Karin Timour later recalled that "we had this whole series of teach-ins and we started just reading documents and learning about how is health insurance structured….But we were really, really focused…in the first, I would say, six months to a year, we didn't spend any time at all on Medicaid. It was all looking at private insurance."[49] She also emphasized the fact that within the committee were "health insurance industry professionals who weren't really on board with the whole idea of a single payer healthcare like England or Canada or any other developed country."[50]

That focus allowed them to campaign to encourage providers to improve their policies, and allow more HIV-positive people to access insurance coverage. ACT UP demonstrated outside Empire Blue Cross and Blue Shield to force them to improve the provisions of their open enrollment policy, which at the time had no stop-loss cap (that being

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[48] For full details of Starkey's case, see Starkey papers, AIDS discrimination 2 boxes.

[49] Karin Timour interview with Sarah Schulman, 5 Apr. 2003, ACT UP oral history project, interview no. 15, page 9. Available at http://www.actuporalhistory.org/interviews/index.html

[50] Timour interview, 56.

the financial point at which Blue Cross would pay all medical expenses and the insured person would no longer have to pay a co-payment and deductible). The demonstration also got Blue Cross to put in writing a commitment that HIV status was not in itself a pre-existing condition and therefore excludable from coverage.[51] The insurance committee filed lawsuits in all fifty states against the National Air Traffic Controllers' Association, whose disability insurance would not cover AIDS if acquired from sex or drugs, and enough state insurance commissioners agreed to hear the case to force NATCA to change its policy. They also made common cause with other patient advocacy organizations such as the Multiple Sclerosis Society, Cancer Care, and the Heart Association to lobby against insurance discrimination, a collaboration that culminated in the umbrella group New Yorkers for Accessible Health Coverage. Bolstered by the involvement of other, less socially stigmatized groups, NYAHC successfully lobbied the New York State Legislature to pass the Open Enrollment Community Rating law of 1992. The new law mandated open enrollment all year round in New York State, so anyone purchasing insurance could not be refused on medical grounds, and premiums were community rated rather than experience rated, amongst other provisions.[52] This major legislative breakthrough demonstrated the impact well-connected lawyers and insurance experts, alongside tireless campaigning of a wide variety of activists, could have on a massive and well organized industry.[53] Yet it also encouraged many insurance companies to cease selling health insurance in the State, and did nothing to tackle the glaring gaps in health coverage elsewhere in the country.

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[51] Ibid, pages 11-12. An open enrollment policy was one you could acquire without a medical questionnaire, usually for a limited period of time during the year.

[52] In addition to permanent open enrolment, also known as "guaranteed issue," the New York law banned insurers from charging different premiums to different group policy members (experience rating), and allowed employees moving to new policies credit from their previous coverage when exposed to waiting periods against pre-existing conditions in new policies. Pre-existing condition waiting periods could be no longer than 12 months, and the law applied to individuals and to small businesses of up to 50 employees. See Timour interview, 56-57.

[53] Ibid, 41-43. Timour credited Mark Scherzer, consulting attorney for GMHC, with providing the legal know-how to lobby for the bill.

The insurance committee eventually became the insurance and health care access committee, a development spurred on in large part by the number of women entering ACT UP with experience of the women's health or anti-poverty movements. Karin Timour recalled the case of Natasha Gray, "one of the people that had this little group and they all kind of coalesced and…took over our meeting and they said, you must deal with Medicaid, you must deal with public entitlements. And we were like, we've got enough on our plate with insurance, you know." Gray spearheaded efforts to publicize ways in which PWAs could access the Medicaid system.[54] Risa Denenberg, a prominent women's health activist who was part of the ACT UP Women's Committee's efforts to expand the AIDS definition to include medical conditions affecting women with HIV, recalled gendered power relationships that characterized ACT UP politics: "just the political issue was that these men, despite the fact that they were gay men, felt very privileged, and felt like they could do anything, and didn't have a real sense of history, most of them, of movements, or of health movements."[55] Terry McGovern, who came into ACT UP after tackling AIDS-related cases through her work as a poverty lawyer, noted the vital importance of what she termed "the poverty lens on HIV," and remembered how "there wasn't the expertise among…the gay male groups to deal with, you know, women with kids, and kind of the poverty stuff that – poverty law, and dealing with public housing and all that stuff, it's a whole separate field."[56] These women spearheaded a campaign to widen the government's definition of AIDS to include women and the poor who often did not display the same symptoms of HIV infection as middle class white men, and who were denied access to the Medicaid and welfare systems. "The majority of people who were not (and still are not) being counted are people who are poor, have little access to health care (including drug rehabilitation), do not have primary care physicians or

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[54] Timour interview, 19-21.

[55] Risa Denenberg interview with Sarah Schulman, 11 July 2004, ACT UP Oral History Project, number 093, 31-32.

[56] Terry McGovern interview with Sarah Schulman, 25 May 2007, ACT UP Oral History Project, number 076, 12.

access to expensive testing," argued the authors of an ACT UP information packet on AIDS, women, and poverty in November 1990.[57] The fact that the turn towards questions of poverty and gender was led overwhelmingly by women some eight years after the first recorded AIDS cases further highlights the forces of class and gender privilege at work in health care activism during the 1980s.

## "Health Care Is/Ought to Be a Right": The ambiguous legacy of AIDS health care politics

In his paper pressing ACT UP members to vote to stage a protest at the Food and Drug Administration in 1988, activist Jim Eigo used a phrase – "healthcare is a human right" – that would become a slogan of AIDS activism by the end of the decade. He later recalled that his paper "was the first time, I think, that ACT UP officially articulated it, but it was very much…what the majority of the floor felt, and…was something that we could ally ourselves with many people outside of the gay world and the AIDS world."[58] In late 1991, ACT UP Golden Gate held a conference under the banner of "health care is a right," claiming to be engaged in a battle to "revolutionize the healthcare delivery system in this country."[59] The horrific sight of thousands of people dying in agony without recourse to decent health care drove a wide variety of citizens into organizations like ACT UP, united by rage at a system poorly equipped to tackle a major public health crisis.[60] Some public health officials shared the view that the AIDS crisis had brought the limitations of the US healthcare system into sharp relief to the extent that some sort of reform was inevitable. "There are many, many

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[57] ACT UP information packet "Women Don't Have AIDS, They Just Die from It," 6 November 1990, Women and AIDS Collection, Education Awareness 1990-95 file, Stonewall Library.

[58] Jim Eigo interview, 5 Mar. 2004, ACT UP Oral History Project, number 047, 34.

[59] ACT UP Golden Gate general meeting agenda, 26 Nov. 1991, ACT UP Golden Gate papers, UCSF special collections, general meeting and other documents file.

[60] See Deborah B. Gould, *Moving Politics: Emotion and ACT UP's Fight Against AIDS* (Chicago: University of Chicago Press, 2009).

serious problems in the health care system overall," argued the director of the California Department of Health Services in testimony to a State Senate select committee in 1989, "and AIDS probably couldn't have come at a worse time….So…we would like to use AIDS also as a vehicle to perhaps develop some better models of how we provide health care overall." He advocated financing care "through a combination of public and private means that distributes the burden of that care equitably among the payers and encourages a cost effective and compassionate delivery of services."[61] Both the Reagan-appointed Presidential Commission on AIDS and the subsequent National Commission appointed by Congress in 1989 made the same argument following a mountain of testimony on the ways in which the experience of PWAs as medical subjects had rendered them vivid symbols of a healthcare regime in crisis.[62]

Yet with a Republican in the White House and little political support for what remained primarily a crisis of the socially marginalized, there was little serious chance of a major public assault on the nation's compartmentalized and dysfunctional health care system. AIDS activists and their few allies in legislative politics were forced to focus their efforts on maintaining access to the private system, as well as lobbying to gain Medicaid coverage for those without insurance coverage. No appeals to notions of rights could match the economic and political power of a vast insurance industry or the indifference of much of America's political class.

At the same time, however, political conflict over the health needs of PWAs revealed a struggle between queer Americans and conservatives over the social status of sexual

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[61] Dr Kenneth Kizer testimony at Hearing of California Senate Select Committee on AIDS, 31 Mar. 1989, Steve Morin papers, Box 6, file 9.

[62] See final report of Presidential Commission on HIV in Commission papers, National Archives II, College Park, Box 1; Press release of National Commission on AIDS, 28 June 1993, "Commission closes after four years: final report faults government leadership," National Commission papers, National Archives II, Box 1, press releases file 3 of 3.

minorities in the wake of the civil rights revolutions. Both sides viewed private health insurance as a totem of social citizenship and mainstream Americanism. Whereas gay rights advocates saw private insurance as a way of shielding the ramshackle welfare system from becoming overwhelmed while furnishing gay men with the trappings of middle class respectability, conservatives saw insurance as the lynchpin of heteronormative capitalism under threat from a stigmatized alien other. Surgeon General Everett Koop's mildly worded exhortation to insurers to put public health concerns ahead of strictly financial ones was immediately condemned by Reagan conservatives as "an outrageous meddling in the insurance question," and was "straight homosexual propaganda, lifted out of their tirades."[63] One angry evangelical made explicit the link between the religious right's portrayals of gay Americans as "sexual sinners" and economic concerns, angrily urging Koop not to use "taxpayer money to finance the treatment of AIDS patients," and not to "elevate AIDS to the standing of a civil rights issue. For example, insurance companies must be able to set premiums and grant (or refuse) insurance coverage on the basis of risk. Otherwise, the innocent will unjustly pay for the benefits of AIDS patients."[64] In a bizarre but telling intervention, Reagan's Assistant Attorney General Richard Willard told a business group that he feared HIV-positive people were seeking out employers "to become eligible for their generous health, disability, and death benefits," and in the absence of mandatory HIV testing employers should limit health benefit packages for new employees.[65] The association of "innocence" with heteronormativity was an economic as well as cultural ideological trope.

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[63] Bill Dannemeyer to Gary Bauer, 6 Mar. 1987, including copy of Koop's speech to California legislature, Ronald Reagan papers, Ronald Reagan Presidential Library, record file OA19222, AIDS VIII file 2 of 4.

[64] Alan Plumley to Everett Koop, 11 Aug. 1987, Koop papers, National Library of Medicine, Bethesda, Box 55, AIDS evangelical opposition file.

[65] Unattributed clipping, "Group demands Justice official resign for remarks," Starkey papers, AIDS discrimination box 2, National Gay Rights Advocates file 1987-8.

For many gay rights advocates at the forefront of campaigns to secure health care for PWAs, accessing private coverage was a direct attack on conservative attempts to consign sexual dissidents to the status of economic as well as social outcasts. They operated in the context of an era of severe cuts to public services and in the knowledge that the welfare state had always been inadequate and ill-suited to serve more than a tiny fraction of society. Mark Senak, legal services director of GMHC, framed the question of "who will pay" for the health costs of AIDS in terms of integrating sexual minorities into full citizenship. "Are we so cold to the interests of our citizens that we would sanction such a great number of our citizens to spend down their own assets on their medical treatment in order to qualify for Medicaid?" he asked in his testimony to the New York State Commission of Insurance in 1987 on plans to ban HIV testing by insurers. "While it has traditionally been their business to discriminate in issuing such insurance, when a business practice by the corporate citizen so dramatically affects the public good on such a variety of levels, the corporate citizen must yield….Corporations have rights, they also have obligations to the citizenry they serve."[66] Establishing the rights of PWAs as citizens in the context of private capitalism was a necessary and yet problematic step in the evolution of civil rights politics in the Reagan era.

Its limitations as a tool for realizing the radical potential of AIDS politics to dovetail with wider critiques of economic inequality quickly became evident. ACT UP insurance committee member David Peterson's decision to change the slogan on some stickers from "Health Care is a Right" to "Health Care Ought to Be a Right" in advance of a planned demonstration at the Met Life building was emblematic of the impact of a politics of respectability and social inclusion on queer protest.[67] Like other equality movements before them, middle class gay activists struggled to reconcile an ongoing struggle for legal equality

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[66] Testimony of Mark Senak to Commission, 25 June 1987, GMHC papers, Box 48, insurance issues 1986-9 file.
[67] See Timour oral history, 55-56.

with broader debates over socio-economic inequality.[68] The long association of public welfare with the social outcast in mainstream politics and the seemingly immovable power of private capitalism in health care blunted any rhetorical commitment to universal access. While it is true that the experience of other polities with more expansive state health care systems suggested greater access did not solve problems of state-sanctioned discrimination on its own, it certainly provided a much clearer path to ensuring all PWAs secured treatment.[69] The battle over health care access presaged later struggles over questions of gay marriage and its attendant economic benefits and underlined the robust relationship between notions of legal equality and the market.

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[68] A telling comparison is with the early women's Equal Rights Amendment battle in the 1920s, when legal formalists became estranged from those pushing for social protections for working women as well as a simple commitment to legal equality. See Joan Zimmerman, "The jurisprudence of equality: The women's minimum wage, the first Equal Rights Amendment, and Adkins v. Children's Hospital, 1905-1923," *Journal of American History*, 78:1 (June 1991), 188-225.

[69] See Murray Pratt, "The defence of the straight state: heteronormativity, AIDS in France, and the space of the nation," *French Cultural Studies*, 1998, 9:28, 263-280; Christophe Broqua and Olivier Fillieule, "The making of state homosexuality: How AIDS shaped same-sex politics in France," *American Behavioral Scientist*, 2018, 61:13, 1623-1639; Virginia Berridge, *AIDS in the UK: The Making of Policy, 1981-1994* (Oxford: Oxford University Press, 1996), especially Part 2. In the US, the emergence of a state-centered approach to LGBT health tended to focus on questions of research rather than treatment. See Steven Epstein, "Sexualizing governance and medicalizing identities: the emergence of 'state-centered' LGBT health politics in the United States," *Sexualities*, 2003, 6:2, 131-171.

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