

FORUM

Health Care Capitalism and the Precarious Right to Bodily Autonomy in the United States since the Rights Revolutions

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In May 1990, in the first case of its kind, the National Gay Rights Advocates (NGRA) secured a California court judgment prohibiting an insurance company from discriminating on the basis of sexual orientation. Great Republic Insurance Company had been using a supplemental questionnaire to screen out “occupations that do not require physical exertion ... such as florists, interior decorators, and fashion designers,” as well as to use applicants’ marital status, “living arrangements,” and medical history to assess the likely risk of their exposure to the human immunodeficiency virus (HIV) when denying health care coverage.¹ That same year, Mobilization for Youth (MFY) Legal Services in New York filed a class action lawsuit on behalf of women living with HIV who had been denied access to Social Security benefits because the government did not recognize their HIV-related conditions as qualifying for state health care coverage under the Medicaid program.² In one sense, the cases were starkly different: one sought to protect the privately insured from discriminatory scrutiny on the basis of their sexuality while the other attempted to bring a protected class of people into public view to make a claim to health care. Yet both reveal an important truth about the concept of rights in an American context. The structure of the U.S. health care system, one based on private insurance for most and a threadbare, convoluted system of categorical assistance and public insurance for children, the disabled, and the elderly, has shaped Americans’ experience of their own sexuality and bodily autonomy in ways arguably unique to the United States. The public/private hybrid in health care has dramatically curtailed the capacity of those outside the heteronormative family structure to realize their demands for full equality in the wake of the rights revolutions. Efforts to secure a right to sexual or gender identity have foundered on the rocks of the health care system when faced, for example, with a public health crisis like HIV or a lack of health insurance plans willing to fund gender-affirming health care.

To demonstrate the complex relationship between sex-based rights and the politics of distribution of health care services, I chart three dimensions to sexual health in the United States since the 1970s. The first concerns the economic imperative at the heart of the self-help health movements, as activists strove to provide affordable, accessible care for women and lesbian, gay, bisexual, transgender, and queer (LGBTQ) people often at the margins of the mainstream health care system. The second shows how the risk calculus of the private health insurance marketplace reinforced and recalibrated the marginalization of sexual minorities of

¹NGRA press release, May 3, 1990, unnamed folder, box 1, National Gay Rights Advocates Papers, Gay, Lesbian, Bisexual, Transgender Historical Society, San Francisco, CA.

²“Women with AIDS Demand Rights,” *Workers World*, Apr. 9, 1992; and Terry McGovern Interview 076, ACT UP Oral History Project, May 25, 2007, 23, www.actuporalhistory.org/numerical-interviews/076-terry-mcgovern (accessed Feb. 17, 2023).

all socio-economic groups in the late twentieth century, a process made highly visible by the HIV crisis but already in motion before then. Finally, I explore how the U.S. welfare system was structured to limit its reach to as few people as possible in ways that disproportionately impacted women living with HIV during the 1980s and early 1990s. These stories highlight the fragility of an individual's right to sexual freedom without a health system predicated upon universal access.

The idea that gendered health care needed to be available to all regardless of socio-economic status demonstrated the close relationship between a politics of individual rights and of distribution of resources. The self-help health movement of the 1970s that sprang out of second-wave feminism and gay liberation aimed to empower people to understand their bodies and provide health care services tailored to their needs. The proliferation of clinics, volunteer groups, and grassroots political organizations devoted to the health and wellbeing of women and sexual minorities combined the promotion of education and empowerment with efforts to ensure access to all who needed services.³ Women's and LGBTQ clinics advertised free or subsidized care, based on ability to pay, and many accepted Medicaid as well as private insurance. For some, particularly those focused on women's health needs, self-empowerment and access to care were inextricably linked. "Two societal conditions are largely responsible for the fact that women in general are not well served by our health care system," wrote a founding member of a San Francisco women's clinic in the late 1970s: "the sexism of many physicians" and diminished access arising from "women's general lower economic status—we earn 58.5 cents to every dollar earned by men."⁴ Women exploring their own bodies in the 1970s, "working to learn about health care in an attempt ... to take care of ourselves and our own people," constantly referenced the economic dimension of their activism. Early member of the Los Angeles Feminist Women's Clinic Frances Hornstein recalled self-help activists visiting and distributing flyers asking for a five-dollar donation: "That was too much money, I thought in my 'health care should be free' thinking. I didn't relate that \$5.00 to the \$25.00 I had paid the previous year for a Pap Smear, a painful pelvic examination and some suppositories for an infection."⁵ A lesbian clinic at San Francisco General Hospital in the late 1970s was dependent on volunteer health workers and a \$10 donation from patients, with a sliding scale for those unable to afford that amount.⁶

At the same time, the fact that health care was a commodity in the United States gave sexual health and identity an economic value that impacted the cultural politics of sexual liberation. Collecting fees from patients in nonprofit clinics was vital to the financial sustainability of many, but exchanging health services for money also formed part of a process of legitimation for those coming to terms with their sexuality. When informing staff of an effort to tighten up processes for collecting payments from those seeking mental health treatment at the Homophile Community Health Service in Boston in 1977, the director noted that money "will certainly continue to be an important issue for clients in therapy. We will inform therapists when clients seem to be having trouble around paying.... Certainly, many clients act out around money and these are clinical, as well as administrative, concerns."⁷ Explicitly linking the rehabilitative function of therapy to economic self-reliance illustrates the central role of money

³See Katie Batza, *Before AIDS: Gay Health Politics in the 1970s* (Philadelphia, 2018); Jennifer Nelson, *More Than Medicine: A History of the Feminist Women's Health Movement* (New York, 2015); and Wendy Kline, *Bodies of Knowledge: Sexuality, Reproduction, and Women's Health in the Second Wave* (Chicago, 2010).

⁴"History of Women's Alternative Health Services," box 91, folder 5, Phyllis Lyon and Del Martin Papers, GLBT Historical Society Archives, San Francisco, CA [hereafter Lyon-Martin Papers].

⁵Frances Hornstein, "Lesbian Health Care," Lesbians and Health Care file, Sexual Minorities Archive, Holyoke, MA [hereafter Sexual Minorities Archive].

⁶"SFGH Lesbian Clinic: Popular but Poor," *Synapse*, Oct. 26, 1978, box 92, folder 5, Lyon-Martin Papers.

⁷Susan Rosen memo to therapy staff, Nov. 22, 1977, box 1, folder 61, John C. Graves Papers, Northeastern University Archives and Special Collections, Boston, MA [hereafter Graves Papers].

in the emergence of the sexual health movement in this period. The financial aspect of legitimation and recognition extended to health care professionals as well as patients: a 1982 survey by the National Lesbian and Gay Health Foundation of seventy-two “lesbian and gay counselling centers” across the United States noted that only four centers had all paid staff, and that a “vast number of lesbians and gay males give untold hours to help their fellows.... While the altruism is more than praiseworthy, it does contrast with the non-gay/lesbian world where free counselling is available only through government sponsorship (so that all therapists are paid). Perhaps some day all of the counsellors ... can get just payment for their Herculean efforts.”⁸ Defining the undeniably second-class status of non-heteronormative health care in these terms further demonstrates the interrelationship of “recognition” and “distribution” in the politics of sex/gender in the specific context of the U.S. health care market.⁹

The heavy reliance of most Americans on private insurance to fund their health care needs has also shaped the politics of bodily autonomy. The management of actuarial risk has consistently required people to reveal their bodies to public scrutiny and to provide or deny treatment and rights dependent on risk-based factors.¹⁰ The HIV-AIDS crisis provides the starkest example, as insurance companies routinely used HIV testing to deny access to funded care or even attempted to screen out claims based on professions or cohabiting status that might indicate an assumed sexual identity and thus risk of HIV.¹¹ Yet what we might call the insurance closet concerned more than the association of sexuality with risk. Even when able to access private health insurance, claimants worried about becoming visible to employers or co-workers. The Director of the Boston mental health clinic discussed earlier wrote in November 1979 that “despite the advantages of using insurance to pay for therapy,” many clients were reluctant to claim, fearing “that their employers will find out they are in therapy, or that they are being seen by a therapist at a gay clinic, or they are being treated for homosexuality.”¹² More than a decade later, AIDS Coalition to Unleash Power (ACT UP) Boston’s insurance subcommittee, whose members informally referred to themselves as “the uninsurables,” wondered how to “help prevent people from choosing *not* to use their insurance services; we don’t want to scare people away from using the insurance they do have,” due to worries about their HIV status being used as a way to cancel their coverage if they dared to make a claim. “Paying cash,” they reflected, “is a kind of fear and denial.”¹³

Paying cash could also be the only way of claiming genuine rights to “a body of one’s own,” as much private insurance has continued to refuse to pay for health care for transgender Americans on the spurious grounds that gender-affirming treatment was not “medically necessary.”¹⁴ The idea of “Do It Yourself care” to support trans* identity affirmation gained

⁸“Survey of Lesbian and Gay Counselling Centers, 1982,” box 11, folder 42, National Lesbian and Gay Health Foundation Records, Rare and Manuscript Collections, Cornell University Library, Ithaca, NY.

⁹Thinking of rights claims in terms of their legal “recognition,” on one hand, and their “distribution” in economic terms, on the other, is central to the work of political philosopher Nancy Fraser. See landmark essays in Nancy Fraser, *Fortunes of Feminism: From State-Managed Capitalism to Neoliberal Crisis* (London, 2013).

¹⁰See Tom Baker and Jonathan Simon, eds., *Embracing Risk: The Changing Culture of Insurance and Responsibility* (Chicago, 2002); and Richard V. Ericson and Aaron Doyle, *Uncertain Business: Risk, Insurance, and the Limits of Knowledge* (Toronto, 2004).

¹¹Jonathan Bell, “Between Private and Public: AIDS, Health Care Capitalism, and the Politics of Respectability in 1980s America,” *Journal of American Studies* 54, no. 1 (Feb. 2020): 159–83.

¹²Susan Rosen to clients, November 28, 1979, box 1, folder 61, Graves Papers. Rosen assured clients that complete confidentiality would be assured when accessing insurance coverage.

¹³“The ‘Uninsurables’ Report,” June 5, 1990, box 4, folder 28, ACT UP Boston Records, Northeastern University Archives, Boston, MA. Emphasis in original.

¹⁴For the appropriation of Virginia Woolf’s concept of gendered autonomy, I credit Patricio Simonetto, *A Body of One’s Own: The Making of Sex Change in Argentina, 1900–2012* (Austin, TX, 2023). For a discussion of barriers to health care for transgender Americans, see “Healthy People 2020: Transgender Health Fact Sheet” and attached citations, Trans and Health file, Sexual Minorities Archive.

impetus from “insurance exclusions [that] contribute to widespread self-medication of hormones by transgender people who feel the urgent need to medically transition.”¹⁵ While self-affirming self-help care remains as important a part of the women’s and gender-nonconforming rights movements as it was in the early days of the sexual liberation era, the privatized model of institutional health care heightens the urgency of efforts to fight for bodily autonomy outside the confines of that system.

Yet the public social safety net has also been constructed to exclude a right to sexual freedoms and equality from its regulatory embrace. From its origins in the veterans’ pensions of the post-Civil War era and the Social Security Act of the 1930s, the welfare system has privileged the heteronormative family unit and the elderly at the expense of single people, those without children, and LGBTQ+ people.¹⁶ Centered on the need to protect children, the severely disabled, and the aged, the system was particularly ill-suited to the needs of women and sexual minorities in the wake of the rights revolutions. State authorities consistently linked the rationing of public resources to the disciplining of people’s bodies. In 1977, the Food and Drug Administration (FDA) essentially banned women “of child-bearing potential” from participating as subjects in early phase clinical research or drug trials.¹⁷ This had the effect of erasing women from much state policy, especially concerning their access to welfare, while reinforcing the notion that women were procreators first and autonomous beings last. As the federal medical establishment (the FDA, Centers for Disease Control [CDC], National Institutes for Health) determined the criteria for defining eligibility for Social Security programs for those classed disabled—the only route to Medicare/Medicaid coverage for people without children or under the age of sixty-five—the lack of understanding of disease progression or drug efficacy in women during the 1980s had a devastating impact on their experience of the HIV-AIDS crisis. Many disease manifestations of HIV in women were not recognized by medical and Social Security bureaucrats as being related, and indeed the CDC stressed how conditions such as vaginal thrush were common and therefore not appropriate for an epidemiological benchmark for HIV surveillance (this rationale also explained the exclusion of tuberculosis—the most common disease manifestation of HIV worldwide—from the CDC definition, despite it affecting huge numbers of people living with the HIV virus, especially the impoverished in communities of color).¹⁸ HIV-AIDS rapidly became an intersectional crisis of gender, race, and class due to the explicit link between scarcity or rationing of social welfare and state surveillance of the gendered body. While some gay men became visible to the state through their early association with diseases that came to define HIV, many others remained invisible until a concerted multiyear campaign was launched to widen the state’s definition of HIV and AIDS in the 1990s. The shadow cast by the 1977 FDA restrictions on women’s health care access well into the

¹⁵“Healthy People 2020 Transgender Health Fact Sheet,” 2. See also Jules Gill-Peterson, “Doctors Who? Radical Lessons from the History of DIY Transition,” *The Baffler*, no. 65, (Sep.–Oct. 2022): 7–15. It should also be noted that between 1981 and 2014, the federal government banned the use of federal funds for gender-transforming surgery and care.

¹⁶Margot Canaday, *The Straight State: Sexuality and Citizenship in Twentieth-Century America* (Princeton, NJ, 2009); Edward Berkowitz, *America’s Welfare State: From Roosevelt to Reagan* (Baltimore, 1991); and Theda Skocpol, *Protecting Soldiers and Mothers: The Political Origins of Social Policy in the United States* (Cambridge, MA, 1992).

¹⁷Katherine A. Liu and Natalie A. Dipietro Mager, “Women’s Involvement in Clinical Trials: Historical Perspective and Future Implications,” *Pharmacy Practice (Granada)* 14, no. 1 (Jan.–Mar. 2016): 708. doi: 10.18549/PharmPract.2016.01.708. The ban followed the well-publicized thalidomide scandal of the 1960s, in which pregnant women prescribed the drug gave birth to babies with severe birth defects.

¹⁸ACT UP information packet, “Women Don’t Have AIDS: They Just Die from It,” Nov. 6, 1990, Box 1, education and awareness 1990–95 file, Women and AIDS Collection, Stonewall Library, Fort Lauderdale, FL; and Jonathan Bell, “Rethinking the Straight State: Welfare Politics, Health Care, and Public Policy in the Shadow of AIDS,” *Journal of American History* 104, no. 4 (Mar. 2018): 931–52.

1990s highlights the broader consequences of the state's prioritizing of reproductive function over the autonomous bodily rights of women.

Thinking about sex and gender-based rights through the lens of health care discloses the connections and affective synergies between different rights movements (cisgender women or trans people, or the various categories contained under the LGBTQ+ umbrella) due to the discriminatory and exclusionary workings of the U.S. health care system. It also suggests that homophobic, misogynistic, or transphobic legal or cultural discrimination based on misrecognition and innate prejudice has been in constant negotiation with the way social goods related to bodily autonomy have been (mal)distributed. While other health systems have also discriminated when assigning priorities for services outside the parameters of the heteronormative nuclear family, the burden imposed by the U.S. public/private hybrid has had a particularly heavy impact on women and LGBTQ+ people. Even before the rollback of gender rights signalled in the recent *Dobbs* Supreme Court decision, it was clear, as Mary Ziegler shows in her contribution to this forum, that the existence of a legal right did not always translate into an ability to access gender-based health care. The absence of a universal right to health underscores the ever-present fragility of the broader range of privacy-based rights ostensibly advanced after the seemingly landmark decision in *Roe v Wade*.