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Shifting Priorities in US AIDS Policy

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“A hopeful society acts boldly to fight diseases like HIV/AIDS, which can be prevented, and treated, and defeated,” President George W. Bush declared in his 2006 State of the Union address. The president specifically called for Congress to reauthorize the Ryan White CARE Act as well as to provide new funding to address the ongoing problems of access to care, including “waiting lists for AIDS medicines in America.” Yet a distinct ideological stamp would accompany funding. “We will also lead a nationwide effort, working closely with African American churches and faith-based groups, to deliver rapid HIV tests to millions, to end the stigma of AIDS.”¹ It was not the first time the president had declared HIV/AIDS to be a top policy priority as well as the means of advancing a conservative agenda.

Only three years earlier the president had argued, “We have the opportunity to save millions of lives abroad from a terrible disease,” in the January 2003 State of the Union “Seldom has history offered a greater opportunity to do so much for so many.”² Some twenty-plus years into the largest epidemic in history, few could disagree. But many people argued that the speech had more to do with domestic politics than with compassion, especially when the president tied aid to highly ideological abstinence-only, rather than evidence-based, AIDS prevention approaches. Today, even this most conservative of US presidents can bolster his credentials as a humanitarian by associating his administration with the struggle against global AIDS.³ Yet from the earliest days, a push and pull between competing ideologies has characterized the policy debate about HIV/AIDS.

HIV/AIDS policy and the politics of AIDS have always been loaded with double meanings. Although many features of HIV/AIDS policy in the United States are unique, public policy created to address the epidemic cannot be understood without considering larger social and economic trends as they influence allocation of resources, budgets, and public administration. Much of

US HIV/AIDS policy has been guided by notions that people with AIDS face “exceptional” circumstances and should be treated outside of traditional public health approaches to the outbreak of disease.⁴ Even in the most politically conservative of times, AIDS activists have made headway when other interest groups experienced cuts. For example, the budget for the 1990 Ryan White CARE Act, which provides funds for AIDS-related services in the United States, expanded almost tenfold—from \$220 million to \$1.9 billion—through three presidential administrations and despite power shifts in Congress over a decade and a half.⁵ By 1996, the year Aid to Families with Dependent Children (AFDC) was “reformed”—meaning guarantees of funding for poor families were reduced, thereby radically transforming a cornerstone of the US social safety net—the Ryan White CARE Act was reauthorized with *increased* funding. This pattern was expected to continue with 2006 reauthorization of the Care Act, although few of the increases would come close to matching increased health expenses.⁶

HIV/AIDS policy in the United States has never been beyond the influence of larger policy trends involving the privatization of social welfare services, expanding income inequality, the lack of nationalized health care, dwindling Social Security provisions, a housing crisis, and the inordinate incarceration of people of color and those who are poor. Not unlike the old “poor law” approach to charity work and social welfare provision, HIV/AIDS policy is still enacted with a moralizing approach aimed at social control rather than actually addressing or alleviating conditions of poverty, such as lack of housing and inadequate health care, experienced by low-income people.⁷

Bearing these considerations in mind, this chapter presents a brief history of advocacy around HIV/AIDS policy in the United States. This history falls into three phases: (1) community organizing and mobilization during the late 1980s, (2) treatment and legislative breakthroughs through the mid-1990s, and (3) the imposition of social control following the treatment advances of the late 1990s. As the mobilization of the late 1980s and early 1990s shifted with legislative and treatment breakthroughs—owing to the advent of highly active antiretroviral therapy (HAART)—both the issues and the methods of fighting the epidemic changed.⁸ As consensus about the exceptional nature of AIDS has dwindled, much of HIV/AIDS policy has shifted from tolerance to coercive approaches. For the sake of brevity, this survey of domestic HIV/AIDS policy omits a number of issues, including blood donation, the struggle for the Global AIDS Fund, global trade policies, rural AIDS policy, and the AIDS advocacy struggles of southern states in the United State.⁹ Instead, this chapter focuses on events in the states of New York and (to a lesser degree) California, where the largest number of people in the United States with HIV/AIDS are found, using them to illustrate the changes in AIDS policy and the forces underlying them.

Mobilization and Organizing

The first phase of the response to HIV/AIDS involved community organizing, mobilization, and the establishment of a network of service providers to help those getting sick—primarily gay men in Los Angeles, New York, and San Francisco. Along with gay men, those at highest risk for HIV/AIDS included socially vulnerable populations such as Haitian immigrants, injection drug users, sex workers, and low-income people of color. Because of the marginalization of these populations, organizing around the epidemic took on an inherently ideological character. This organizing emerged in part as a response to the ongoing backlash against the gains of the gay liberation years of the 1970s, which AIDS threatened to wipe out. Just three years before the first reports of the disease appeared in 1981, queers¹⁰ had effectively beaten back antigay campaigns by Anita Bryant and John Briggs as well as a national movement by the Christian Right to repeal recently passed gay rights laws. Harvey Milk, one of the nation's first openly gay public officials, was elected to the Board of Supervisors in 1977 and helped construct a San Francisco progressive coalition of gays, immigrants, and labor as part of the response to the early efforts of the new Christian Right. The nationally renowned San Francisco model of community-based care for people with HIV/AIDS emerged from this grassroots response.¹¹

Service Provision as AIDS Activism

The first AIDS service organizations (ASOs)—the San Francisco Kaposi's Sarcoma Foundation (later renamed the San Francisco AIDS Foundation) and Gay Men's Health Crisis (GMHC) in New York City—were born of this grassroots organizing and the concurrent contraction of the gay liberation movement. Gay liberationists had struggled throughout the 1960s and 1970s to end homophobia, not to build organizations to fight it. Both impulses can be seen in the dual missions of the early ASOs: to end the AIDS epidemic and to build organizations to better serve those infected and affected by the disease. Many ASOs struggled to function as quasi-social movement organizations, pursuing the broader goal of social change through the delivery of services. ASOs, like all social movement organizations, had to contend with inherent competing ideological pressures. Their social-movement orientation was sustained by values and an emphasis on social change, whereas their agency orientation focused on caring for those in need of services with minimal resources. All the while, those involved fought to gain increased government funding on the local, state, and national levels.¹² Along the way, ASOs had to contend with the challenge of blending their movement emphasis with their agency orientation, which depended on a detente with the prevailing

institutions of a health and service bureaucracy that was often regarded as the target of AIDS activists.¹³ The struggle to balance these pressures would become more complex, especially as polices were adopted that increased funding for AIDS service organizations.

How to Have Policy in an Epidemic

The focus of much of the early prevention and service work was the urgent need to keep people alive until a cure for AIDS was found. Although the first responses to the epidemic were characterized by panic and hysteria, a primary goal of early prevention activists was to beat back the moralistic view of AIDS as a punishment from God. The fact that AIDS seemed to specifically target sexual and racial minorities, already considered outsiders in US life, only contributed to this view. Yet as routes of transmission were clarified, New York City activists Michael Callen and Richard Berkowitz worked with Dr. Joseph Sonnabend to write “How to Have Sex in an Epidemic,” a forty-page pamphlet outlining an approach to safer sex, now recognized around the world as a model that allows for both intimacy and protection. The birth of “safer sex” resulted in a novel policy approach, embraced in urban centers, to keep new infections under control until a cure could be found.¹⁴

These early years were characterized by neglect on the federal policy level. Ronald Reagan, the US president under whose watch the epidemic first exploded, failed to utter the word *AIDS* for the first six years of his two terms in office. This neglect translated into countless abuses on the clinical level. The first HIV/AIDS clinical trial, testing AZT, took place in 1985 and 1986. Nineteen members of the placebo group died within the first six months of this placebo-controlled, double-blind study—designed to produce the “cleanest” data—before the study was halted. The blunt reality was that the early AIDS clinical trials were designed with “a particularly nasty way of determining whether a drug worked: whether the patient died.”¹⁵

Policies Driven by Consumers, Not Professionals

The treatment of people with HIV as a stigmatized group spurred the emergence of a radical advocacy movement propelled by the passionate involvement of people living with AIDS who fought the image of people with AIDS as docile “victims.” In an indicator of trends to come, Michael Callen, who had helped invent safer sex, and other people with HIV/AIDS disrupted the orderly meeting of the Second National AIDS Forum held in Denver in 1983. Their action was similar to the way Science for the People had disrupted the smug confines of scientific conferences during the Vietnam War.¹⁶ While in Denver, Callen, Bobbi Campbell, and others drafted a statement—that became known as the Denver Principles—on the rights of people with AIDS

to enjoy civil rights, healthy sex lives, and self determination, just like everyone else. In so doing, they laid the groundwork for a people with AIDS advocacy movement that successfully challenged the prevailing hierarchical medical model of a passive patient–godlike doctor relationship. Much of the work involved in building systems of health care for people with HIV is rooted in the successful advocacy of the Women’s Health Movement, which challenged patriarchal doctors and male-dominated systems of care.¹⁷ The roots of ACT UP, born in 1987 under the rubric “ACTION = LIFE,” can be located within this work.

Throughout the 1980s, the social and economic repercussions of the epidemic only escalated. The years 1985 and 1986 were marked by bathhouse closures from coast to coast, a Supreme Court decision (*Bowers vs. Hardwick*) that upheld state-level sodomy laws, and increased pressure from the resurgent Christian Right. In July 1986, Lyndon LaRouche introduced a California ballot initiative, Proposition 64, that aimed to quarantine people living with AIDS while barring them and those at risk from a range of jobs. Proposition 64 lost by a wide margin that November, but the attack it represented was very real.¹⁸

Recognizing that no one else would do the work, queer activists pushed back.¹⁹ The initial service-oriented mobilization around the epidemic was followed by a second angrier wave in the late 1980s that gave birth to ACT UP, the Names Project, World AIDS Day, and a wide range of grassroots political actions.²⁰ Activist Richard Elovich recalled some of the disruptions that put the medical bureaucracy on notice:

My engagement began when, as a representative of ACT UP’s Treatment and Data Committee in 1989, I heard a researcher dismiss addicts as a “non-compliant population” while explaining why they were not represented in clinical drug trials. I remember standing up in an auditorium at the New York Academy of Medicine, not three blocks from the methadone clinic where I had been a client seven years before, identifying myself with other addicts and challenging this notion. I’d stood often in front of audiences as a performer, but never before as a heroin addict in recovery.²¹

The point was that effective activism could be thought of as a public performance, with audiences including policymakers, allies, and the public.²² ACT UP helped create a sense that the AIDS crisis required action by policymakers. To do this, its work was marked by a theatrical flair. Building on the lessons of the US civil rights movement, ACT UP cultivated a creative tension that stimulated action. When faced with a policy impasse, the group made use of effective disruptions—such as the interruptions of formal policy bodies that Elovich described—that broke down barriers to proactive policy formation. These disruptions created the climate in which policymakers felt compelled to move.²³

To be successful in dealing with the health crisis, activists realized that they needed to challenge a medical model that sought to control people, all the while

forcing them to wait for the bureaucracy to work. While some died waiting, others created a new approach to HIV/AIDS prevention that sought to meet gay men, drug users, prostitutes, and others at risk where they had sex, shot up, and made a living. Syringe-exchange policy was born within this milieu. The case of syringe exchange incorporates ACT UP's use of street theatrics, a sense of urgency, and political savvy to achieve a desired policy outcome. As Richard Elovich recalled: "When the city's pilot needle exchange program became so politicized that it was shut down in 1990, ACT UP founded an illegal program, jokingly referred to as its longest running civil disobedience."²⁴ Throughout the late 1980s and 1990s, ACT UP successfully redeployed the Gandhian/civil rights era repertoire of nonviolent civil disobedience techniques to fight for effective therapies for people with HIV/AIDS. With the mantra "drugs into bodies," the group successfully fought for treatment, services, and expedited approval of HIV/AIDS drugs. Elovich elaborated on the dramaturgical approach used to advance policy goals in the area of syringe exchange: "Operated entirely by volunteers, we performed weekly, going out to distribute clean needles, condoms, and bilingual information about health services to thousands of injection drug users at risk for AIDS in the Bronx, East Harlem, the Lower East Side."²⁵ What emerged within this work was a practical approach to the provision of service: "Our services were informed by the theory of 'harm reduction,' the belief that change is not all-or-nothing, and that even incremental changes could be valuable in helping people save their own lives."²⁶

Having established a community-based strategy to preventing the spread of the disease, the group pushed for widespread use of this intervention. Again, the group turned to theater to stimulate a successful policy outcome. Elovich explained, "The next phase of the performance was in front of a judge. I, along with eight other AIDS activists, [was] arrested when we openly challenged the law that criminalized needle possession."²⁷ The activists based their defense on the legal principle that the minor legal violation of needle distribution was justified by preventing the larger harm of increased rates of HIV/AIDS among injection drug users, their families, and communities. In their defense, these activists brought extensive data and expert witnesses (drug users themselves) to testify to the lack of effective treatment and the efficacy of the syringe-exchange approach. The judge agreed with the argument, finding syringe exchange to be a justifiable medical necessity. And the state of New York legalized the exchange of clean syringes by syringe-exchange programs that were monitored by the state Department of Health in 1990. Despite a federal ban on syringe exchange and other frank approaches to HIV/AIDS prevention,²⁸ needle exchange became an established approach to HIV prevention work. As data poured in, needle exchange was embraced by many health professionals, and even a few politicians.²⁹

From 1987 through 1995, ACT UP led the second wave of AIDS activism. The group's victories resulted in more responsive public policies

involving expedited Food and Drug Administration (FDA) approval of life-saving HIV drugs, a successful drive to push the first Bush administration to expand the definition of AIDS to reflect the different ways the disease affects women, the recognition that housing is an AIDS issue, and the adoption of harm reduction rather than moralist approaches to HIV prevention.

The push for a more humanistic policy strategy toward containing the disease was a core component of ACT UP's work. When the AIDS epidemic first began, traditional approaches toward the outbreak of unknown diseases called for tracing contacts, reporting names, and implementing other policies that compromised the civil liberties of those with disease. Conservative commentator William F. Buckley even proposed that people with HIV/AIDS be tattooed.³⁰ Yet AIDS activists suggested that circumstances around the AIDS epidemic were unique; thus they required exceptional treatment approaches. The term *AIDS exceptionalism* was born from this idea. Within this policy framework, anonymous HIV testing, rather than contact tracing, became the standard practice across the country.

With AIDS activists playing a watchdog role, AIDS exceptionalism thrived, yet not without its ongoing battles. In the late 1980s, for example, Stephen Joseph, then head of the New York City Department of Health, called for mandatory HIV testing and heavy crackdowns on prostitutes, thinking queer New York would not fight his attacks on the most disenfranchised. In addition, Joseph proposed that the Department of Health report the names of all those who tested HIV positive and contact their sexual partners. ACT UP member Jim Eigo organized the response to this proposed policy, leading an ACT UP affinity group that picketed all of Joseph's appearances. When every AIDS and gay-lesbian-bisexual-transgender organization in the city opposed names reporting, then-mayor Ed Koch, worried about the political fallout, pulled the proposal.³¹ ACT UP's strategy of identifying clear goals, organizing around those goals, and using the momentum of a social movement allowed the group to mobilize resources to influence countless HIV/AIDS policies and their implementation across the United States.

Legislation, Treatment, and the Rise of the AIDS Industry

The late 1980s through the mid-1990s witnessed the advancement of a number of public policies, laws, and services, followed by successful treatments for people living with HIV/AIDS who could afford the drugs. Among these were the passage of the Ryan White CARE Act in 1990, the passage of the Housing Opportunities for People with AIDS (HOPWA) Act in 1992, the approval of state syringe-exchange laws across the country, and the consolidation of the Department of AIDS Services (DAS) in New York City in 1996. The Ryan White CARE Act distributes federal moneys to community-based AIDS serv-

ice organizations, following the San Francisco model of AIDS service delivery.³² The act includes the AIDS Drug Assistance Program (ADAP), which pays for medications for people with HIV/AIDS. HOPWA is a program of the U.S. Department of Housing and Urban Development (HUD) designed to provide federal funding for housing and supportive services for people living with HIV/AIDS. HOPWA was a response to organizing by groups, including the ACT UP affinity group Housing Works, which insisted that adequate housing was an AIDS issue.³³

Although the Ryan White CARE Act was perhaps the most sustained expansion of the US social safety net since 1981, many viewed it as a short-term solution to the AIDS crisis. As advocates translated their gains into funding, many groups became not-for-profit organizations, and grassroots activists bemoaned their movement's co-optation. Social services supplanted advocacy as many organizers shifted from critique to coexistence with the advent of funding and the election of a potentially sympathetic new Democratic presidential administration in 1992.

The pattern is not unfamiliar.³⁴ Funding often has the effect of creating a means-ends inversion as policymakers focus on continued funding rather than alleviating the issue or problem—AIDS, poverty, lack of housing—for which they had sought money in the first place. As Joel Handler and Yeheskel Hasenfeld noted: “The welfare bureaucracy itself becomes a powerful interest group aimed to preserve and enhance itself.”³⁵ As the AIDS epidemic progressed, many ASOs began orienting themselves toward perpetuating their existence over the long term rather than calling for a cure. This shift necessitated building stronger infrastructures to support increased funding viewed as necessary for service provision.³⁶

A definitive battle of the second decade of AIDS activism involved the institutionalization of the epidemic. Government subcontracting can offer nonprofits fair and manageable means with which to provide services, but in other cases these contracts can function as a tool of demobilization. To build infrastructure and accommodate funding requirements, many organizations look to the insights of professionals instead of to their grassroots bases. Daniel Patrick Moynihan described this phenomenon as the “professionalism of reform.”³⁷ The process unfolds as advocacy groups come to favor administrative remedies over grassroots mobilization and direct action. Countless movements—including the civil rights, environmental, and consumer movements—witnessed this pattern in their organizations in the 1970s as lobbying and legal strategies supplanted community organizing. The result was an approach that favored the work of elite professionals instead of the rank and file.³⁸ Although ASOs do follow this trend, there are those that buck the trend.

Direct action and community mobilization helped secure many of the funds necessary to address the needs of people with HIV/AIDS. Other organizations such as New York's Housing Works, a spin-off from the ACT UP

Housing Committee and the country's largest minority-controlled ASO, have used direct action to complement its service provision aims. Although provision of individual services historically presented a major dilemma for social movement organizations, Housing Works is part of a trend that suggests direct-action political advocacy is consistent with, and even a necessary component of, service provision.³⁹

Perhaps the greatest shift in the HIV/AIDS policy environment occurred in the summer of 1996. The Eleventh International Conference on AIDS, held in July 1996 in Vancouver, British Columbia, brought news of the first significant progress in treating people with HIV/AIDS. Although no cure was announced, the breakthroughs of 1996 helped push HIV disease that much closer to becoming a chronic, manageable condition. Manageable, that is, if you lived in the developing world and could afford the new medications. ADAP programs were pushed to their limits to pay for expensive new protease inhibitor drugs. After fifteen brutal years and a previous international AIDS conference in 1994 that had produced little more than a call for reassessment, Vancouver offered real hope and a new set of policy questions. Who would have access to care? Where would financially impoverished people with AIDS, who had once died rapidly, live for the long term? In the ensuing years, housing and mental health issues would increasingly top the domestic HIV/AIDS policy agenda.

The ethical imperative of AIDS activism has always been that health care is a right and that the US health-care delivery system is deeply flawed. While many activists were pushing for a cure for AIDS, others were working toward a more universal goal of health care for all during the first years of the Clinton administration. Yet the shift from conflict to coordination was anything but smooth. Many contend that ACT UP failed to adapt to the shift in the political environment that accompanied the election of Bill Clinton as president in 1992. Former ACT UP member and founder of Treatment Action Group Mark Harrington recalled that:

1992 was a really interesting transition. A lot of people were really involved in activism. Even up till the day before the election of Clinton, the day of the election we had a political funeral where we delivered Mark Fisher's body to Bush headquarters here in New York. I don't think that anyone really thought that Clinton would win. And when he did win, I don't think most activists were prepared from a policy landscape for how to push forward in this new environment. And so on issues like health care there really wasn't a push from the left or the progressive side of the streets in terms of demanding national health care. Everybody acted like all of a sudden we lived in a socialist Western European State, where the state would put more money into AIDS and Clinton would take care of you. And everything would just be fine. And they didn't create enough support around policy changes around say the immigration issue or needle exchange or many other things. While research did very well under Clinton, a lot of the basic activist issues

or prevention didn't bear so well. And now we're back in the situation, in many ways quite dire, of course now we have highly active antiretroviral therapy.⁴⁰

By the end of 1994, the Clinton health care initiative died in committee in a Congress controlled by Democrats. The same pharmaceutical companies that ACT UP had long fought worked with the American Medical Association, the insurance industry, and political conservatives to generate a climate of fear that helped sink the proposed Clinton health-care plan. After the 1994 midterm elections, the Republican Party took control of the 104th Congress, and universal health care was put on the back burner of the national policy agenda. At the same time, the state of California passed its "three strikes" law that mandated automatic jail time for three-time offenders, regardless of the crime. The law set in motion a nationwide reallocation of resources from social services and education to criminal justice and the prison industry.⁴¹ In the coming years, AIDS policy would find itself becoming less and less of an exception to these larger policy trends.

National health care had been a cornerstone of an approach to domestic policy designed to reconstruct and politically fortify the US social safety net by providing expanded earned-income tax credits to reduce poverty, government funding for child care and health care, and only then time limits for services.⁴² In 1995, President Bill Clinton abandoned this ambitious agenda, declaring that "the era of big government is over."⁴³ The following year, the president signed away AFDC, a cornerstone of the US welfare system, and replaced it with Temporary Assistance to Needy Families (TANF). TANF ensured lifetime limits of five years to those on public assistance with few of the supports, such as government funding for child care or universalized health care, that could make the transition from public assistance to work manageable.⁴⁴ As AIDS became more and more entwined within the mosaic of US poverty, the shrinkage approaches provided by the US welfare state for broad-based antipoverty policies increasingly affected people with HIV and their families.

Shortly after Clinton's reelection in 1996, Robert Reich, a primary architect of the unsuccessful Clinton blueprint for a renewed social safety net, bid Washington adieu with a last word on US social policy. Reich warned that no social problem facing the country was more important or vexing than the gap between rich and poor.⁴⁵ Yet domestic social and economic inequalities only widened during the 1990s economic expansion, and poverty rates and the number of uninsured Americans only increased with the economic downturn during the ensuing Bush administration years.⁴⁶ Urban health mirrors overall socioeconomic health in countless ways.⁴⁷ "HIV tracks along all the fault lines of political economy and culture of the planet," Jeanne Bergman, a veteran AIDS and human rights activist, now with Health GAP, explained. "All health issues generally do but AIDS because of its connection specifically to

drugs and sex and sex work more than most things. And because it kills it's sort of super heated in a way that some other public health issues are not."⁴⁸ Yet few involved with AIDS service provision were thinking in such structural or cultural terms, beyond "getting another piece of the pie" during Ryan White funding reauthorizations.⁴⁹

In the fall of 1997, Project Inform, a San Francisco-based HIV/AIDS treatment advocacy group, released a position paper calling for a recognition that the US system of health-care delivery continued to be a disaster, regardless of AIDS funding. The paper noted that although there had been a revolution in treatment for people with HIV/AIDS, there had been no similar innovative thinking about the future of AIDS services. Instead, many once-radical AIDS activists had been "bought off by the special programs and funding erected in response to our crisis-driven advocacy."⁵⁰ Much of AIDS funding was based on the idea of AIDS exceptionalism and powerful interest groups' support for a unique continuum of services for people with HIV/AIDS. Yet people with other chronic illnesses, such as cancer, did not enjoy similar levels of funding and services. Without advancing the idea of national health care for all Americans, it was hard to imagine AIDS funding lasting.

While such programs may meet the individual needs of people in crisis, they do not solve the underlying problems that made AIDS such a crisis in the health care system. AIDS put the deficiencies of the system in the spotlight. But instead of fixing the system, we ended up settling for a literal sideshow of programs, while leaving the system as deficient as ever. We may have gotten the basics of what was needed for some people with AIDS, but lost the opportunity to solve the problems on a larger scale.⁵¹

Instead of focusing on renewing ADAP and Ryan White funding, Project Inform called for AIDS activists to work in coalition with advocates for people with other chronic diseases "to create solutions which can last a lifetime," without leaving people with HIV/AIDS perched on the fragile political limb of annually renewed programs and services.

Jeanne Bergman, who worked as policy analyst with Housing Works during the latter half of the 1990s, suggested that discussions of AIDS exceptionalism must also address issues of social inequality. Even with AIDS exceptionalism, disparities in economic resources among affected populations determined access to care. "Privileged people" found easy "access to care, in contrast to the denial of the most basic human needs that poor people got," Bergman explained. Nowhere was this inequality more glaring than in the provision of housing services. "With the New York City Department of AIDS Services (DAS), that was so intense," Bergman explained. She continued:

DAS was created because a class of young men, who were accustomed to living well, were getting sick and could no longer afford their homes and the

way they had been living. And unlike other poor people, these men were basically designated exceptional. And they could get a rent allocation of \$2000.00 a month, something unheard of for somebody who is poor. I think everybody should get that. But the racism of this system and the classism of this system, it would so baldly recognize the needs of these wealthy white gay men who were categorically deserving of a higher level of tax payer support and just funding. What it was created to be and what it came to be were two totally different things. The whole point of DAS initially was to spare white gay men from the indignities of the welfare system. At the time, as the recipients of benefits changed, it became actually more of a barrier than a point of access. But initially, if everybody who was sick could get their entitlements more easily that would have been Heaven but it's not what it was intended to do.⁵²

As HIV/AIDS affected higher and higher percentages of communities of color, inequalities in access to health only became more pronounced. As people with HIV came to be seen as more and more from low-income communities of color rather than privileged affluence, policies shifted from exceptionalism toward systems of monitoring, revelation, social control, and criminalization.

Social Control

With the failure of AIDS advocates to embrace a universal health care strategy—and with no cure in sight—HIV/AIDS policy became a victim of larger policy trends, including expanding income inequality, criminalization over prevention, increased surveillance, privatization of services, and a growing federal deficit that made the advancement of bold social policy nearly impossible.⁵³ Clinton's two terms in office concluded with national health care far off the national political agenda as George W. Bush became president in 2001. Within this policy vacuum, HIV/AIDS policy increasingly promoted control of those who utilized AIDS services. Although much of the foundation for the legislative gains in the area of HIV/AIDS services was created within a context of crisis, the advent of HAART, an effective HIV/AIDS treatment relying on “cocktails” or groups of medications that prevented HIV from spreading in the body, basically transformed HIV disease into a chronic condition for those who could afford treatment, preventive health services, and housing. As the crisis mentality crumbled, so did the liberal consensus supporting funding for HIV/AIDS service provision and tolerance for frank HIV prevention messages, even on a local level.

Debate Around Safer Sex Policy

The shift in prevention policy began with news of a second wave of HIV infections in the mid-1990s. Accumulating data confirmed what advocates

already knew: that many were rejecting the “wear a condom or beat it!” and “safe sex is hot sex” slogans that had become the cornerstones of the safer sex movement.⁵⁴ Along the road, the trend of gay men telling their funders what they wanted to hear—that they had given up promiscuity—began to fade.⁵⁵ Wearing a condom for every sexual act for a lifetime was an incredibly complex endeavor. Many admitted that the “wear a condom every time” ethos of the mid-1980s was proving difficult to sustain over the long term. And these challenges to prevention were occurring at a time when the gap was widening between social justice-minded queers who saw the epidemic spreading around disparities of sex, race, class, and gender and assimilationist-minded gays living longer, healthier lives.⁵⁶

The 1995–1998 period was marked by struggles over the right direction for HIV prevention policy as one report after another detailed increased rates of HIV transmission.⁵⁷ Questions about HIV prevention spurred a public debate akin to the “sex wars” over pornography and sexual choice that took place among feminists in the United States from the late 1970s through the early 1990s. Much of the debate began after the 1996 Vancouver AIDS conference, as reports emerged that new combination antiretroviral drug regimens, including protease inhibitors, could reduce HIV to undetectable levels in the blood. The *New York Times* reported that the new viral load tests presented a challenge to HIV prevention efforts. The story implied that a new cohort of young men now assumed that if viral loads were low, then HIV was no longer active in the body and one could have unprotected sex. The story was fraught with misconceptions. In it, AIDS activist and ACT UP founder Larry Kramer condemned this view: “If you test low on the PCR [viral load test], some people are using this as an excuse to literally go out and have unsafe sex again, assuming incorrectly that they have no more virus in their system.”⁵⁸

In early 1997, the *New England Journal of Medicine* reported that 26 percent of HIV-negative men were less concerned about HIV risk than they had been before recent treatment advances. Furthermore, 13 percent said they were willing to take more chances than they had taken in the past, and 15 percent conceded they had already done so.⁵⁹ Although troubling to many, these reports infuriated a small number of gay journalists. The idea that gay sex was responsible for a new wave of infections inspired conservative gay journalists to embrace the reactionary contention that gay sexuality was dangerous not only for homosexuals but also for society at large.⁶⁰

Shortly after the Vancouver conference, conservative gay commentator Andrew Sullivan published an essay, “When Plagues End,” that suggested that AIDS was basically over now that gay men had access to treatment. By making the social, political, and economic violence of HIV/AIDS epidemic appear a thing of the past, the essay set ACT UP’s work back by a decade. Sullivan’s essay spoke to problems of history and memory. What would be the lessons of the AIDS crisis years? According to Sullivan, only with AIDS did

gays gain respectability, despite the “irresponsible outrages of Act-Up.” Sullivan openly worried about the “post-AIDS” gay lifestyle, noting that “people feared that the ebbing of AIDS would lead to a new burst of promiscuity, to a return to the 1970s in some joyous celebration of old times.” The question was, would the notions that “queer sexuality equals contagion” and that gay men needed to be domesticated be the legacy of the crisis years?⁶¹ Gabriel Rotello, a gay New York journalist whose book, *Sexual Ecology*, was to be published the following year, suggested that they would be. “A very effective way to reduce the contact rate is to make relationships more attractive,” he explained shortly after the Vancouver conference. “One of the best ways to do that is to show people how they can exist as couples safely.”⁶²

A number of prevention and advocacy groups—including one that dubbed itself SexPanic!—formed to respond to this reactionary thinking. SexPanic! member Kendall Thomas responded to Sullivan’s message thus: “I simply reject the narrative about disco balls and loud dance music providing the undercurrent for this almost Dionysian story of infection because it suggests to me that gay men, rather than a virus, led to this epidemic.”⁶³ For Thomas and other social justice-minded activists, the unfolding events looked like the makings of a sex panic. A cornerstone of the group’s response was to challenge the idea of “good gay” versus “bad gay,” promiscuous queer versus responsible gay man, worthy versus unworthy persons with AIDS.

A split between the worthy and the unworthy characterizes the entire history of social policy in the United States. Although the “worthy poor” typically receive sympathy and support, the “unworthy poor” are left to fend for themselves. The latter are seen as morally weak for indulging in habits different from those of the majority. Thus, they get what they deserve.⁶⁴ The same process unfolded as “worthy” people with AIDS, who contracted HIV from blood transfusions or dentists or before transmission routes were clarified, were distinguished from “unworthy” drug users and those who had unsafe sex despite “knowing better.” Like most of this country’s social problems, this split is accentuated by race, gender, and income inequality.⁶⁵ Along the road, HIV/AIDS policy was shifting toward black and white.

Race, Prevention, and Criminalization

One part sex, another part race, and a third part misinformation propelled a panic that transformed the public response to the epidemic in the late 1990s. A key undercurrent involved the changing demographics of the epidemic. Race, sex, and notions of “otherness” have always played a complex role in the formation of HIV/AIDS policies. Majority Action, an affinity group of the original ACT UP/New York, contended that people of color had always comprised the majority of HIV/AIDS cases. Yet only in the mid-1990s did HIV/AIDS policy respond to this reality. As AIDS epidemiology shifted, the

disease and the policies surrounding it became ever more racialized. Yet this was more of a continuation of a long-standing trend. Elements of class, race, and heterosexism have always contributed to denials, secrecy, and blame around the epidemic. In the early days of the epidemic, ethnic groups felt safe around an epidemic, which the media projected as affecting mostly gay white men. This denial continued when new “at risk groups” included communities of color and intravenous drug users. Along the road, differing groups continued to feel “safe” because of appearances that their group was no longer affected. Given the stigma and shame over high-risk behaviors—including unsafe sex, injection drug use, and nonmonogamy—these groups did not adequately examine at-risk behaviors that continued to place them at risk.⁶⁶ The shifting demographics of the epidemic created a unique set of political challenges as issues of race, sex, and homophobia made further effective mobilization around the epidemic more complex.⁶⁷

Studies suggested that African Americans accounted for more than half of new AIDS cases, with people of color making up an increasing percentage of those infected with HIV. While injection drug use became the predominant mode of transmission among African Americans, black men who did not identify as “gay,” yet had sexual contact with other men, were also a factor. Stories about “down low” men bringing the epidemic home to their wives triggered age-old anxieties about predatory, overly sexualized black men. These stories, in turn, gave journalists fodder to “manufacture drama” about “dangerous black men attacking women.”⁶⁸

In 1997, these tensions found their own poster boy. News reports that year were dominated by stories about Nushawn Williams, a young African American man who was said to have knowingly had unsafe sex with a number of women in upstate New York. One tabloid labeled him “the One Man AIDS Epidemic.”⁶⁹ On September 5, talk show host Geraldo Rivera addressed the topic in a segment of his CNBC program entitled “Privacy for Predators, We Ask?”:

The AIDS assassin, so-called, ah . . . alleged, Nushawn Williams. The latest on his story and what his story has done to affect confidentiality in the midst of the AIDS epidemic. Nushawn Williams, the nightmare of the 90s, the Willie Horton of the AIDS epidemic, the alleged AIDS assassin who has allegedly been spreading the HIV epidemic across a 300-mile swatch of New York State, probably infecting dozens of women. . . . What about syphilis? What about tuberculosis? Why is AIDS so different, especially now that it has become a treatable condition? Why have we, because of political pressure, singled out this one disease as having special privileges? AIDS has lost the reason to be treated differently, that is my belief. There is no difference between AIDS now than any other chronic conditions.⁷⁰

Rivera’s discussion offers a glimpse of the ways the issue of race and sex undermine the case for AIDS exceptionalism. Later in the show, Rivera asked

conservative commentator Ann Coulter why she had advocated tattooing the genitalia of people infected with HIV. Despite “the Nazi associations,” Coulter suggested, “in a way it actually deals with a lot of the concerns: having your employers know, having your friends know, having your family know.” After all, Coulter explained, “the only person who knows is the one point of contact where you can transmit a deadly disease . . . um . . . there are labels on mattresses, on hamburger meat, on cigarettes.”⁷¹

As debate about Williams’s actions swirled, he came to embody many of the tensions around AIDS exceptionalism, civil liberties, effective HIV prevention, criminalization of HIV transmission, and calls for mandatory names reporting of HIV-infected individuals. Predictably, backlash followed. New York State Assembly member Nettie Mayersohn proposed legislation calling for fifteen-year prison sentences for “knowingly exposing a partner to HIV.”⁷²

The year 1998 produced the gravest legislative threats to the AIDS community since the earliest days of the epidemic. In the months after the Williams case came to light, GMHC shifted its position from opposition to acceptance of name-based HIV reporting. In response, the New York–based Hispanic AIDS Forum, the American Civil Liberties Union (ACLU), SexPanic!, and ACT UP argued that names reporting would eliminate anonymous testing and thus would discourage many from seeking treatment if they knew their names would be reported to the government.

In the days following GMHC’s policy shift, consensus about the need for civil liberties for people with HIV/AIDS was lost. The AIDS advocacy community split between civil liberties advocates, such as ACT UP and SexPanic!, and those, such as GMHC, that depended on federal moneys with strict stipulations.⁷³ Despite community outrage, policy forums, pickets at the New York City HIV Planning Council, and activists who chained themselves to the offices of the New York City Health Department, names reporting and mandatory contact tracing became state law.⁷⁴ New York State, with the largest HIV/AIDS caseload in the United States, is considered a trendsetter for HIV/AIDS policy. Its shift paved the way for the adoption of names reporting by other states.

In the wake of the Nushawn Williams case, HIV criminalization swept the country. By 2000, laws penalizing failure to disclose HIV status to a partner (even if having protected sex) were on the books in Alabama, Arkansas, California, Connecticut, Florida, Georgia, Idaho, Illinois, Indiana, Iowa, Kansas, Louisiana, Maryland, Michigan, Minnesota, Missouri, Montana, Nevada, New Jersey, North Dakota, Ohio, Oklahoma, South Carolina, Tennessee, Texas, and Washington.⁷⁵ In some locales, prostitution consequently was prosecuted as a crime equal to attempted murder if HIV was involved. As Lawrence O. Gostin, director of the Georgetown University–Johns Hopkins Program on Law and Public Health, noted: “We’ve moved from a period where civil rights and civil liberties for a person with HIV prevailed to a compulsory and punitive approach.”⁷⁶

AIDS Policy, Surveillance, and the Therapeutic State

Without the help of a mobilized queer constituency, consensus around AIDS exceptionalism, safer sex, and safeguards for the civil liberties of people with HIV/AIDS faded. Instead, AIDS services became part of the increasingly contested political terrain. Andrew Polsky described the process: “We—officials and citizens alike—look to public human services to deal with forms of distress that arouse our compassion by altering forms of behavior that unnerve us. Inaction in the face of, say, family violence is unacceptable, and we are at a loss for other policies to address the situation. We therefore invite public authority to probe the inner recesses of people’s lives.”⁷⁷

Instead of exceptionalism, people with AIDS were increasingly treated to the “rituals of degradation and surveillance” that accompany people who have traditionally been included on the public welfare rolls.⁷⁸ In the ensuing years, policies around names reporting, case surveillance, and AIDS criminalization exploded across the country. As aid was translated into an arena of control, those dependent on public services were most affected. Public assistance in the United States historically has been aimed at promoting “traditional” family norms. Critics describe the process as “public patriarchy.” This normalizing effect extends itself as the state battles deviance among those in the public arena.⁷⁹ After 1996, HIV transmission was increasingly approached as a deviant act deserving punishment and state surveillance.

Much of the shift in HIV/AIDS policy can also be attributed to funding pressures. From 1995 to 1996, federal funders, including the Center for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), proposed a move from mathematical models based on percentages of AIDS cases to more specific case counts. Until this point, AIDS counts had been based on estimated cumulative numbers with a degree of repetition. The CDC and HRSA wanted more accurate information and data on which to base future Ryan White CARE Act allocations, changing the way states and urban areas received moneys. Name-based reporting policies soon followed. “The result was really damaging,” recalled Keith Cylar, co-president of Housing Works, the nation’s largest minority-controlled AIDS service organization. “This was where all the criminalization and labeling everyone started.”⁸⁰

Along the road, HIV/AIDS policies shifted away from tolerance and toward coercion and increased surveillance from federal and state funding agencies. Formalizing the process, the CDC announced in April 2003 that the federal government was shifting its emphasis away from preventing new infections in at-risk populations toward expanded testing of people with HIV and their partners. The new initiative would focus on encouraging testing and targeting of HIV-positive people to minimize the spread of the virus. Critics quickly challenged the new approach. The National Association of People

With AIDS (NAPWA) suggested: “Major parts of this initiative appear to respond more to political pressure from the far right than the prevention needs of communities threatened by HIV/AIDS.”⁸¹

For many, the initiative’s emphasis on targeting those already HIV positive smacked of control more than prevention. The CDC confirmed these fears in its April 18, 2003, *Morbidity and Mortality Weekly Report*: “Although many persons with HIV modify their behavior to reduce their risk for transmitting HIV after learning they are infected, *some persons might require ongoing prevention services to change their risk behavior or to maintain change* (emphasis added).”⁸²

Thus community-based organizations funded by the CDC were specifically charged with using their relationships with clients to “elicit number of partners and contact information” for sex or drug use partners during ongoing partner counseling and referral services. The aim of such services was “advancing communication . . . with previous and current partners.”⁸³ Service providers were put in a double bind. Although they realized that funding was at stake, they also recognized that clients may disengage when counseling services are used to “elicit” intimate information.

The CDC’s new policy harkened back to the benevolent investigative methods employed by nineteenth-century social work “friendly visitors” during home visits. The assumption was that those receiving public assistance needed counseling and rehabilitation rather than the same privacy rights enjoyed by other citizens. At its worst, this surveillance of poor people manifested itself in a series of degrading inquiries into the sex lives of women. Typical questions included “When did you last menstruate?”⁸⁴

Names reporting played on the same power of levels of stigma and intimidation, providing CDC-funded service providers surveillance powers not unlike those of the police.⁸⁵ The policy presents a case study for Foucault’s critique of the state’s power over bodies. The argument is familiar enough. By the eighteenth and nineteenth centuries, professionals sought to identify and control the mechanisms of interior life, memories, and so on.⁸⁶ For many people, it is impossible or painful to recall the names of past sex or drug use partners. For others, the risks of reporting the names of sex or drug use partners may include domestic violence or loss of home, family, and shelter. Nevertheless, the CDC emphasizes “counseling” and “eliciting” names. Prevention activists have long suggested that both partners should use safer sex protection and that HIV prevention works best without governmental interference, but the new CDC initiative flew in the face of such community-based-practice approaches.⁸⁷ Despite these deficiencies, this invasive approach only continued with CDC initiatives such as Program Evaluation and Monitoring System (PEMS).⁸⁸

HIV names reporting represented one piece of a larger public health trend resulting in social control over health and reproductive choices. Two days

after taking office, Bush reenacted a Reagan-era gag rule (known as the Mexico City policy) banning US aid to international reproductive health or family planning service providers that offer any information about abortion.⁸⁹ At home, the administration emphasized abstinence-only prevention approaches, despite little or no data showing that they are as effective as comprehensive sex education.⁹⁰

The Bush administration's emphasis on ideology over evidence was becoming a familiar pattern.⁹¹ In 2003, the administration removed language about the well-tested efficacy of condoms as a means of preventing HIV from the CDC's Web sites. But that was just the beginning of an all-out assault on evidence-based HIV prevention programs. Throughout its term, the Bush administration has underfunded comprehensive HIV prevention programs, grilled researchers addressing AIDS and sexual practices, continued a ban on well-established programs such as syringe exchange (although to be fair Clinton never lifted the ban on syringe exchange), and audited AIDS service organizations receiving federal funds that rejected abstinence-based approaches.⁹² And those who rejected such modes of control have increasingly felt intimidated by their funders and contract managers because of these decisions.⁹³

Welfare or Warfare State and Privatized Services

On June 24, 2003, President Bush visited New York City for a fundraiser. Countless groups planned protests to highlight how Bush's focus on war had obfuscated his very real attacks on public services and the civil rights of citizens at home. Leslie Cagan, an organizer with United for Peace and Justice, noted that "the vast sums of money spent on an illegal and unnecessary war against Iraq could have been used to protect the health of women and many others whose safety nets are getting shredded by the Bush administration."⁹⁴

It is impossible to consider the current state of HIV/AIDS policy or the broader US social safety net without considering how the current administration's focus on war and corporate interests is leading to the deterioration of basic public services, including those for people with HIV/AIDS.

Medicare and Medicaid are timely examples. Early in 2003, the Bush administration's Medicare administrator, Thomas Scully, described the program as "an unbelievable disaster" as he laid out details of the president's plan to move some 50 percent of seniors from Medicare into private health plans.⁹⁵ AIDS activists concerned about the future of the US social safety net argued that the bill would prevent Medicaid from acting as an insurer of last resort for poor people.⁹⁶

Like many struggles over services and care for people with HIV/AIDS, this battle involved a struggle between the pharmaceutical and insurance industries—which had gutted the Clinton universal health care proposal—

who were seeking a market-based solution and those who hoped to maintain the government's role in the provision of health and social services. For pharmaceutical companies, market-based solutions allow drug costs to escalate without limit. A drug "cocktail" for a person with HIV costs some \$30,000 per year on the government's tab for those not paying with private health insurance. In spring 2003, the FDA approved Fuzeon, the first of a new class of anti-HIV drugs. The drug's price tag is about \$20,000 per year, twice that of any other individual AIDS drug.⁹⁷ While the HAART drug cocktail of may amount to more per year, there has never been one AIDS drug priced at such a level. People with cancer, heart disease, and other chronic illnesses also pay steep prices for their medications. As drug prices escalate, they place an almost untenable burden on government programs, including Medicaid and ADAP. Medicaid and Medicare are the largest and the second-largest sources for health-care funding for people living with HIV/AIDS.⁹⁸ Some 19 percent of all people with HIV/AIDS utilize Medicare, which in 2002 paid some \$2.1 billion to cover their health care costs.⁹⁹

Debate about drug prices would often dominate the AIDS policy debate. As the push for privatization of Medicaid continued, advocates argued that without a significant subscription drug benefit to help offset costs, government programs such as ADAP would become increasingly unable to provide health-care coverage for people with HIV/AIDS. Already, many cannot obtain HIV medications owing to the vast gaps between available funding, exorbitant drug costs, and the number of people on waiting lists for benefits. In August 2003, two people in West Virginia died while on waiting lists to receive HIV medications through ADAP.¹⁰⁰ A study by the Institute of Medicine of the National Academies of Medicine found that thousands of HIV-positive applicants for care were regularly turned away or disqualified for services each year. The report's core finding was that the federal government should expand its role in providing treatment for low-income people with HIV/AIDS.¹⁰¹ Yet instead of addressing gaps in services, in November 2003 Congress approved Medicare reform heavily favoring the pharmaceutical industry while limiting the government's ability to reduce the cost of medication.

While conservatives push privatization, HIV/AIDS advocates and sympathetic policymakers have struggled to keep AIDS services exempt from the changes overtaking the health care industry. The battle over Medicare privatization points to an increasing elite influence on US social policy. Rather than expand the range of public services, "elites promote the private market as a better source than government for education, health, welfare, and benefits."¹⁰² Devolution, decentralization, subcontracting of government services, vouchers, and privatization have come to serve as "patterns for structuring public policy."¹⁰³ For activists, privatization "represents a thin cover for the private use of public power."¹⁰⁴ As a result of a highly mobilized and connected constituency, HIV/AIDS policy has managed to elude the worst elements of the

trend toward health-care privatization. An example may be instructive. In spring 2003, New York City mayor Michael Bloomberg proposed to subcontract basic case management services for people with HIV/AIDS. For AIDS advocates, the policy smacked of yet another attempt to “abdicate governmental responsibility for providing essential lifesaving services and benefits in a timely manner.”¹⁰⁵ Still the city proposed subcontracting government-based case management and entitlement services into the private sector, where nonprofits could administer these services. Although there is generally nothing wrong with subcontracting basic services, there are certain things the private sector cannot do. The private sector cannot turn on and off public benefits or make decisions about eligibility criteria. Although the private sector can deliver services, subcontracting cannot replace the vital role of government in determining eligibility. In the case of New York City case management services, as has often been the case with HIV/AIDS policy in the city, a highly mobilized coalition of AIDS activists—including members of ACT UP, Housing Works, and small harm-reduction organizations—lobbied, offered counterproposals, protested, and were arrested at City Hall, and eventually the privatization proposal was taken off the table.¹⁰⁶

Conclusion

HIV/AIDS policy in the United States has undergone three distinct phases, from early mobilizations, through advances in legislation and treatment, to a control phase in which people with HIV/AIDS and community-based service providers struggle for autonomy while attempting to preserve the remains of a US social safety net and welfare state. All the while gaps in services continue to grow. In spring 2004, the Kaiser Foundation found that 1,500 people in ten states were on waiting lists to receive services of the AIDS Drug Assistance Program designed to pay for gaps in funding for life-saving medications.¹⁰⁷ Two years later, the Public Health Watch HIV/AIDS Monitoring Project of the Open Society Institute (OSI) published a report claiming that the United States has failed to curb the disease nationwide. The report, *HIV/AIDS Policy in the United States: Monitoring the UNGASS Declaration of Commitment on HIV/AIDS*, presented a comprehensive analysis of the progress in domestic AIDS services and policies. Findings suggested that (1) efforts aimed at addressing the disease remain uncoordinated, with ideological conflict continuing to impede comprehensive approaches to prevention, treatment, and support; (2) some 50 percent of those in need of treatment are not getting it; (3) the rate of new infections remains consistent at 40,000 a year; (3) and the disease continues to disproportionately affect communities of color, gay men and men who have sex with men, injecting drug users, and the poor.¹⁰⁸

Rachel Gugli Guglielmo, of the OSI, elaborated on the disparities in infection rates: “African Americans account for half of new HIV infections in the U.S., despite being less than 13% of the national population, and AIDS is the leading cause of death for African-American women ages 24–34.” She concluded, “These are not the signs of a strong national response to AIDS.”¹⁰⁹ The OSI suggested that a comprehensive national strategy is necessary to address these gaps in care. Such a strategy would require (1) a national focus on clearly stated outcomes, coordinated from the federal level to state and city agencies; (2) a campaign to test, refine, and deliver services to communities of color and other hard-to-reach populations; and (3) evidence-based interventions, including using proven tools such as harm reduction. Such a national strategy would make Medicaid work for poor people by overturning cost sharing and benefit caps; it would increase resources to address a range of health needs, including housing, entitlements, mental health, chemical dependency, and treatment needs; and finally, it would maintain a commitment to research efforts designed to improve on HIV prevention and treatment strategies.¹¹⁰

Yet, as always with HIV policy, competing ideologies impede comprehensive strategies toward treatment and care. As funding for HIV/AIDS continues on a flat line that fails to match either increases in numbers of those infected or costs of care, gaps in the HIV safety net only continue to widen. Yet activism around these problems continues. On May 20, 2004, service providers, AIDS activists, and people with HIV/AIDS converged in what was largely considered the largest AIDS civil disobedience action in Washington since 1987.¹¹¹ The aim of the protest was to assert that “AIDS would not defeat us” while reclaiming the energy that propelled the earliest mobilizations, which helped create the AIDS safety net in the first place. The future of effective HIV/AIDS policy in the United States depends on the success of such broad-based, collaborative mobilizations.

Notes

The author would like to thank Andrew Polsky, Eric Rofes, and Liz Highleyman for careful readings and suggestions for this chapter. This chapter is dedicated to two people. The first is Keith Cylar, an activist who fought to create many of the federal HIV/AIDS policies as well as to enact them within a harm-reduction setting at Housing Works, the nation’s most militant AIDS service organization. The final time I spoke with Cylar in any kind of substantial fashion before his death, he provided the short interview for this essay. The week that revisions for this chapter were due, Eric Rofes, who also offered a careful reading, died. Rofes was a giant in the Gay Liberation Movement who helped teach us that AIDS panic is no reason to forgo the lessons of Gay Liberation. The spirit of Cylar and Rofes, two big leather guys, who liked to play, runs through the impulse to turn AIDS advocacy into a broad-based human rights movement.

1. G. W. Bush, "State of the Union Address by the President," United States Capitol, Washington, DC, January 31, 2006. Available at <http://www.whitehouse.gov/stateoftheunion/2006/index.html>.

2. Ibid.

3. Nicholas D. Kristof, "When Prudery Kills," *New York Times*, October 8, 2003.

4. Chandler Burr, "The AIDS Exception: Privacy vs. Public Health," *Atlantic Monthly* 279, June 1997.

5. Health Resources and Services Administration, *Ryan White CARE Act Title I Manual*, 2003, 3. Available at <http://hab.hrsa.gov/tools/p1.htm>.

6. The Ryan White HIV/AIDS Treatment Modernization Act of 2006 has yet to be approved by either the House or Senate. Without a final act to comment on, this chapter does not consider the ongoing changes to the CARE act.

7. The reference to "poor laws" involves the historic link between the British social welfare policy of "poor laws" and US approaches to social welfare policy that were derived from those laws. For a discussion of the link between these approaches, see Walter I. Trattner, *From Poor Law To Welfare State*, 5th ed. (New York: Free Press, 1995). For a discussion of the link between moralism and social welfare policy, see Joel Handler and Yeheskel Hasenfeld, *The Moral Construction of Poverty* (London: Sage, 1991). For an updated view of this approach referred to in this chapter, see Tony Platt, "The State of U.S. Welfare: Regressive and Punitive," *Monthly Review* 55, no. 5 (October 13–27, 2003).

8. Eric Rofes, correspondence with the author, November 17, 2003.

9. J. Graham, "Fighting AIDS in Our Own Back Yard. The Body," 2004. Available at http://www.thebody.com/asp/mayjun04/fighting_aids.html.

10. Here I use the term *queer* as an abbreviation for gay, lesbian, bisexual, and transgender (GLBT) communities, especially in the case of the communities who fought antigay initiatives. Throughout the rest of this chapter, however, the definition of *queer* will be deployed with a more expansive or universalizing discourse in mind, involving not only GLBT communities but all communities who, as Douglas Crimp noted, have all become a little queerer by their experience of the stigma related to the AIDS epidemic. For a discussion of broad definitions of *queer* as resistance to social, economic, and cultural regimes of the normal, see Michael Warner, "Introduction," and Douglas Crimp, "Right on Girlfriend," in *Fear of a Queer Planet*, ed. Michael Warner (Minneapolis: University of Minnesota Press, 1993). For a discussion of minoritizing/universalizing views of homo/heterosexual identity, see Eve Kosofsky Sedgwick, *Epistemology of the Closet* (Berkeley: University of California Press, 1990).

11. Benjamin Shepard, *White Nights and Ascending Shadows: An Oral History of the San Francisco AIDS Epidemic* (London: Cassell Press, 1997).

12. Eric Rofes, correspondence.

13. Cheryl Hyde, "The Ideational System of Social Movement Agencies: An Examination of Feminist Health Centers," in *Human Services as Complex Organizations*, ed. Yeheskel Hasenfeld, 122–125 (Thousand Oaks, CA: Sage, 1992).

14. For a discussion of the politics of the early years of HIV prevention policy formation, see Richard Berkowitz, *Stayin' Alive: The Invention of Safe Sex, a Personal History* (Cambridge MA: Westview Press/Perseus Books Group, 2003).

15. Patricia Siplon, *AIDS and the Policy Struggle in the United States* (Washington, DC: Georgetown University Press, 2002), 25.

16. Kelly Moore, *Disruptive Science: Professionals, Activism, and the Politics of the War in the United States, 1945–75* (Princeton, NJ: Princeton University Press, forthcoming).

17. I am indebted to Spence Halpern for pointing this out.

18. John Fisher et al. *A Short History of Discrimination Against Gay Men and Lesbians*. Gay and Lesbian Issues and HIV/AIDS: Final Report. Montreal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1998. Available at www.aids-law.ca/Maincontent/issues/gaylesbian/finalreports/gliipa.htm.

19. For a review of ACT UP's early work, see Douglas Crimp and Adam Rolson, *AIDS Demographics* (Seattle: Bay Press, 1991).

20. Shepard, *White Nights and Ascending Shadows*.

21. Richard Elovich, "I'll Hold Your Story, I'll Be Your Mirror," *Artery—The AIDS Arts Forum*. Available at www.artistswithaids.org/artery/symposium/symposium_eloovich.html (accessed September 2, 2004).

22. Daniel Brouwer, "ACT-ing UP in Congressional Hearings," in *Counterpublics and the State*, ed. Robert Asen and Daniel Brouwer (Albany: State University of New York Press, 2001). See also Doug McAdam, "The Framing Function of Movement Tactics: Strategic Dramaturgy in the American Civil Rights Movement," in *Comparative Perspectives on Social Movements*, ed. Doug McAdam, John D. McCarthy, and Mayer N. Zald (Cambridge: Cambridge University Press, 1996); Benjamin Shepard, "Absurd Responses v. Earnest Politics," *Journal of Aesthetics and Protest* 1, no. 2 (2003): 95–115.

23. Benjamin Shepard, "The AIDS Coalition to Unleash Power: A Brief Reconsideration," in *Left Political Movements Today and Tomorrow*, ed. John Berg (New York: Roman and Littlefield, 2002).

24. Ibid.

25. Ibid.

26. For an outline of the clinical applications of this approach, see Patt Denning, *Practicing Harm Reduction Psychotherapy: An Alternative Approach to Addictions* (New York: Guilford Press, 2000).

27. Elovich, "I'll Hold Your Story, I'll Be Your Mirror." **{AU: Correct?}**

28. In October 1987, the Senate passed Amendment 956, sponsored by Jesse Helms (R-NC), prohibiting the Center for Disease Control and Prevention (CDC) from using government money to "provide AIDS education, information, or prevention materials and activities that promote, encourage, or condone sexual activity outside a sexually monogamous marriage (including homosexual activities) or the use of intravenous drugs." Quoted in Siplon, *AIDS and the Policy Struggle in the United States*. For further discussion of the politics of the Helms amendment, see Douglas Crimp, "How to Have Promiscuity in an Epidemic," in *Melancholia and Moralism: Essays on AIDS and Queer Politics* (Cambridge, MA: MIT Press, 2002).

29. Much of New York City mayor Michael Bloomberg's support for needle exchange was based on sound evidence. In winter 2003, the mayor stated: "We also will continue the practice of exchanging syringes. These programs have been operating in New York City for over ten years. The sky has not fallen. Drug use and drug-related crime have not gone up. In fact, they've gone down. And HIV infections among injection drug users, their spouses, and their children have also gone down. A 2002 study by the State Department of Health evaluated 13 syringe exchange programs, nine of which are in New York City, and found that these programs are responsible for at least a 50% reduction, and possibly as much as a 75% reduction, in the rate of new infection for injection drug users." Quoted in Michael Kink, *Housing Works: New York State AIDS Issues Update*, March 17, 2003. Available at <http://www.hwadvocacy.com/update/>.

30. See William Buckley, "Identify All the Carriers," *New York Times*, March 18, 1988, A27.

31. Crimp and Rolson, *AIDS Demographics*, 72–76.

32. Philip Hilts, "\$2.9 Billion Bill for AIDS Relief Gains in Senate," *New York Times*, May 16, 1990, A1, 24. See also Shepard, *White Nights and Ascending Shadows*, 154–159.

33. "Housing Opportunities for People with AIDS (HOPWA)," HUD Office of HIV/AIDS Housing. Available at www.hud.gov/offices/cpd/aidshousing/programs/index.cfm (accessed October 10, 2003).

34. Gareth Morgan noted that the links between critical theory and the study of organizations must address how ideology, information, accounting, and other organizational practices inform control of organizations. Gareth Morgan, *Images of Organization* (Thousand Oaks, CA: Sage, 1997), 406.

35. Handler and Hasenfeld, *The Moral Construction of Poverty*, 8.

36. Benjamin Shepard, "Organizational Changes in the Era of Protease Inhibitors," unpublished Donor's Forum Report, Chicago.

37. This pattern is clearly outlined in Daniel P. Moynihan, *Maximum Feasible Misunderstanding: Community Action in the War on Poverty* (New York: Free Press, 1971).

38. Matthew A. Crenson and Benjamin Ginsberg, *Downsizing Democracy: How America Sidelined Its Citizens and Privatized Its Public* (Baltimore, MD: Johns Hopkins University Press, 2002).

39. For a short discussion of Housing Works' use of direct action and service provision, see B. Shepard, "Bridging the Praxis Divide: From Direct Action to Direct Service and Back Again," in *Constituent Imagination: Militant Investigations/Collective Theorization in the Global Justice Movement*, ed. S. Shukaitis and D. Graeber (Oakland, CA: AK Press, 2006). For a discussion of the complementary use of direct action and service provision, see Fred Brooks, "Resolving the Dilemma Between Organizing and Services: Los Angeles ACORN," *Social Work* 50, no. 3 (2005): 262–269.

40. Mark Harrington, interview with the author, New York, 2005.

41. David Shichor, "Three Strikes as a Public Policy: The Convergence of the New Penology and McDonaldization of Punishment," *Crime-and-Delinquency* 43 (October 1997): 470–492.

42. The theoretical underpinnings for this project can be found in David Ellwood, *Poor Support: Poverty and the American Family* (New York: Basic Books, 1988). For a more detailed picture of this era, see Ellwood's "Welfare Reform as I Knew It: When Bad Things Happen to Good Policies," *American Prospect* 7, no. 26 (May 1, 1997).

43. "The Era of Big Government Is Over," CNN transcript of President Clinton's radio address, January 27, 1996. Available at http://www.cnn.com/US/9601/budget/01-27/clinton_radio/.

44. Lynn Sweet, "Clinton Backs Sweeping Welfare Plan; Bill Ends Federal Guarantee of Benefits," *Chicago Sun Time*, August 1, 1996, 1.

45. David E. Sanger, "The Last Liberal (Almost) Leaves Town; Labor Secretary Reich Offers 'a Last Word' on U.S. Social Policy," *New York Times*, January 9, 1997.

46. Lynette Clementon, "More Americans in Poverty in 2002, Census Study Says; Household Income Falls, Lingering Effects of Recession Hit Hardest at Midwest and Nonwhites, Data Show," *New York Times*, September 27, 2003, A1. See also Robert Pear, "Big Increase Seen in People Lacking Health Insurance, Largest Rise in a Decade; Higher Costs and a Decline in Workplace Coverage Are at Fault, Census Finds," *New York Times*, September 30, 2003, A1.

47. Harvey Brenner et al., "Politics, Policy, and Urban Health." Paper presented at the Second International Conference on Urban Health, New York City, October 17, 2003.

48. Jeanne Bergman, interview by author, {CITY?}, 2006.

49. Shepard, *White Nights and Ascending Shadows*.
50. Project Inform. "The Coming Sunset on AIDS Funding Programs," *PI Perspective*, no. 22, July 1997. Available at www.projectinform.org/cgi-bin/print_hit_bold.pl/pub/22/fullissue.html (accessed October 12, 2003).
51. Ibid.
52. Jeanne Bergman, interview by author, {CITY?}, 2006.
53. Theda Skocpol, *Boomerang: Health Care Reform and the Turn Against Government* (New York: W. W. Norton, 1995). For more on the expanding federal deficit and dwindling social services, see Benjamin Shepard, "AIDS Activism and 'Reagan's Revenge,'" *Radical Society* 29, no. 3 (2002): 26–29.
54. M. Scott Mallinger, "About Anal Sex, Barebacking: Slogans Aren't Enough," *Badpuppy Gay Today*, April 6, 1998.
55. Eric Rofes, *Dry Bones Breathe: Gay Men Creating Post-AIDS Identities and Subcultures* (Binghamton, NY: Harrington Park Press, 1998), 3–73.
56. Benjamin Shepard, "The Queer/Gay Assimilationist Split," *Monthly Review* 53, no. 1 (May 2001).
57. Allison Reddick, "Dangerous Practices: Ideological Use of the 'Second Wave,'" in *Policing Public Sex: Queer Politics and the Future of AIDS Activism*, ed. Dangerous Bedfellows (Boston: South End Press, 1996).
58. Kramer, quoted in David W. Dunlap, "In AIDS Age, Love Can Add Risk," *New York Times*, July 27, 1996, 9.
59. Reported in "LGNy Review '97," *LGNy*, January 19, 1998, 16–17.
60. Richard Goldstein, "The Crackdown on Cruising: Just When You Thought It Was Safe to Be Gay, Police Harassment Is on the Rise," *Village Voice*, July 1, 1997, 36–38.
61. Andrew Sullivan, "When AIDS Ends," *New York Times Magazine*, November 10, 1996, 55, 60.
62. Rotello quoted in Dunlap, "In AIDS Age," *New York Times*.
63. "In the Company of Men: A Roundtable," *Out Magazine*, October 1997.
64. Trattner, *From Poor Law to Welfare State*, 56–57.
65. Rofes, *Dry Bones Breathe*.
66. Cascelles W. Black, "AIDS and Secrets," in *Secrets in Families and Family Therapy*, ed. Even Imber-Black, 358–359 (London: W. W. Norton, 1993).
67. For a more careful review of the issue of race and HIV policy, see Cathy J. Cohen, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (Chicago: University of Chicago Press, 1999).
68. Osborne Duncan, "Down Low's Media Herd Appeal," *Gay City News* (2003), 23, 29; Linda Villarosa, "Speaking Out to Make AIDS an Issue of Color," *New York Times*, December 19, 2000, F7; Leroy Whitfield, "Black Plague: Whites Gain Some Reprieve from HIV, but African Americans Are Dying Faster Than Ever. Here's Why," *Positively Aware* 8, no. 5 (September/October 1997).
69. James Barron, "One Man HIV Epidemic," *New York Times*, November 2, 1997. Available at <http://query.nytimes.com/gst/fullpage.html?sec=health&res=9E02EFD81430F931A35752C1A961958260>.
70. Rivera quoted in ACT UP/New York, "Nushawn Williams Telecasts," 1998. Available at www.actupny.org/alert/Nushawn-TV.html (accessed October 3, 2003). See also Adam Nossiter, "Man Knowingly Exposed 62 Women to AIDS Virus, Health Officials Looking for More Partners," *New York Times*, April 19, 1997; Chris Bull, "Compassion Fatigue," *The Advocate*, May 27, 1997, 42.
71. {AU: Need to specify which source.}
72. ACT UP/New York, "Nushawn Williams Telecasts."

73. Lynda Richardson, "AIDS Group Urges New York to Start Reporting of HIV; A Consensus Collapses," *New York Times*, January 13, 1998, A1. See also Catherine Hanssens, "HIV Reporting May Deter Some from Testing," *New York Times*, January 20, 1998, letters to the editor.

74. ACT UP/New York, "Seven Activists Take Over Department of Health Commission Office to Demand Repeal of Partner Notification Legislation," press release. Information about this action and other demonstrations on the policy is available at www.actupny.org/alert/names.html. See also Benjamin Shepard, "Notes on a Sex-Panic!" *Gaywave*, October 1998.

75. Greg Lugliani, "POZ Annual Givers Guide," *POZ*, December 1998. Available at www.poz.com/index.cfm?p=article&art_id=1883 (accessed October 2003); Laura Whitehorn, "America's Most Unwanted," *POZ*, August 2000.

76. Gostin quoted in Lugliani, "POZ Annual Givers Guide."

77. Andrew Polsky, *The Rise of the Therapeutic State* (Princeton, NJ: Princeton University Press, 1991), 7.

78. Christian Parenti, *The Soft Cage: Surveillance in America* (New York: Basic Books, 2003), 152–153.

79. Handler and Hasenfeld, *The Moral Construction of Poverty*, 6.

80. Keith Cylar, Interview with the author, October 7, 2003.

81. NAPWA quoted in Marcelo Ballve, "Brazil, Not U.S., May Lead World's Fight Against HIV," Pacific News Service, July 21, 2003.

82. CDC, "Advancing HIV Prevention: New Strategies for a Changing Epidemic—United States, 2003," *Morbidity and Mortality Weekly Report*, April 18, 2003, 331.

83. CDC, "Partner Counseling and Referral Services Program Compliance Materials," New York City Department of Health, in the possession of the author.

84. Parenti, *The Soft Cage*, 162.

85. Morgan, *Images of Organization*, 406, and Parenti, *The Soft Cage*, 163.

86. Michel Foucault, *The History of Sexuality: An Introduction*, vol. 1 (New York: Vintage, 1978).

87. For an overview of the debates between those who called for community-based prevention activism and those who called for state-based approaches, see Jim Eigo, "The City as Body Politic/The Body as City Unto Itself," in *From ACT UP to the WTO: Urban Protest and Community-Building in the Era of Globalization*, ed. Benjamin Shepard and Ron Hayduk (New York: Verso Press, 2002). See also Dangerous Bedfellows, *Policing Public Sex* (Boston: South End Press, 1996).

88. "PEMS Won't Give Us the Answers We Need," Community HIV AIDS Mobilization press release, December 20, 2005. Available at <http://www.champnetwork.org/media/CHAMP-Press-Release-Dec-19.pdf>.

89. Nicholas Kristof, "Bush vs. Women," *New York Times*, August 16, 2002.

90. Chris Collins et al. "Abstinence Only vs. Comprehensive Sex Education: What Are the Arguments? What Is the Evidence?" Policy Monograph Series. Progressive Health Partners, AIDS Policy Research Center and Center for AIDS Prevention Studies, AIDS Research Institute, University of California, San Francisco, March 2002. Available at <http://ari.ucsf.edu/pdf/abstinence.pdf>.

91. In August 2003, Representative Henry Waxman (D-CA) produced a report detailing the ways politics subverts basic scientific evidence in government reports and policy to support the ideology of the Bush administration. *Politics and Science in the Bush Administration*, US House of Representatives, Committee on Government Reform—Minority Staff, Special Investigations Division. Available at www.house.gov/reform/min/politicsandscience/pdfs/pdf_politics_and_science_rep.pdf. See also Ted Agres, "Science, Policy, and Partisan Politics; Congressional Report Fuels Debate

over Science and Decision Making," *The Scientist*, August 13, 2003. Available at www.biomedcentral.com/news/20030813/04.

92. Erica Goode, "Certain Words Can Trip Up AIDS Grants, Scientists Say," *New York Times*, April 18, 2003, A18; Mark Sherman, "NIH Questions Researchers About Grants," Associated Press, October 28, 2003.

93. Duncan Osborne, "Abstinence-Only Supported over All Others; Sex Education Under Bush Excludes Contraception, GLBT Issues," *Gay City News* 1, no. 19, October 4, 2003. Available at www.gaycitynews.com/gcn19/abstinence.html.

94. Statement from UFPJ Press Room. Available at <http://www.unitedforpeace.org/article.php?list=type&type=15&offset=20> (accessed November 1, 2006). Noted political scientist Frances Fox Piven echoes these sentiments in *The War at Home: The Domestic Costs of Bush's Militarism* (New York: New Press, 2004).

95. Scully quoted in "Bush's Medicare Plan Seeks to Move Seniors into Private Plans, Doesn't Decrease Prescription Drug Costs," *Daily Mis-lead*, October 29, 2003. Available at www.misleader.com/daily_mislead/Read.asp?fn=df10292003.html.

96. Robin Toner, "Medicare: Battleground for a Bigger Struggle," *New York Times*, July 20, 2003, sec. 4. Michael Kink, "Medicare Conferees Consider Sneak Attack on Medicaid—New York Impact Could be Huge," *Housing Works: New York State AIDS Issues Update*, October 28, 2003; also see "Proposed Medicare Drug Bill Will Slash Drug Coverage for 50,000 Americans Living with AIDS," November 19, 2003, both available at <http://www.hwadvocacy.com/update/>.

97. David Brown, "FDA Approves First in Class of AIDS Drugs, 'Fusion Inhibitor' Will Help People Whose Bodies Resist Current Medications," *Washington Post*, March 14, 2003, A02.

98. Christine Lubinski, Executive Director, HIV Medicine Association, Access Project, Letter to Congress, "Medicare Is an AIDS Issue," September 24, 2003.

99. *Ibid.*

100. *Ibid.*

101. Committee on Public Financing and Delivery of HIV Care, *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White*, Board on Health Promotion and Disease Prevention, Institute of Medicine (Washington, DC: National Academies Press, 2004).

102. Crenson and Ginsberg, *Downsizing Democracy*, 5.

103. *Ibid.*, 202.

104. *Ibid.*, 194.

105. Michael Kink, "Mayor Michael Bloomberg Stuns AIDS Summit with Long-Awaited Initial AIDS Policy Speech, Delivers a Wildly Mixed Bag of Proposals: Threatens to Kill Local Law 49, Push PWAs into Workfare," *Housing Works: New York State AIDS Issues Update*, March 17, 2003. Available at <http://www.hwadvocacy.com/update/>.

Duncan Osborne, "Dissent Mars Bloomberg AIDS Reform Launch," *Gay City News*, March 21, 2003.

106. Frank Lombardi, "AIDS Rally Jams Doors to City Hall," *New York Daily News*, May 15, 2003, 10; Margaret Ramirez, "Arrests in AIDS Rally, 30 Charged as Activists Decry Proposed Budget Cuts," *New York Newsday*, May 15, 2003, A17.

107. Kaiser Family Foundation. Available at <http://www.kff.org/medicaid/index.cfm> (accessed November 20, 2006).

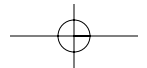
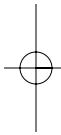
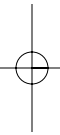
108. "The United States, a Leader in Efforts Against Global AIDS Epidemic, Is Failing to Address the Disease at Home, Says New Report on Eve of UN Global AIDS Summit; Experts, Including Former Surgeon General, Release First Comprehensive Analysis of U.S. Response to Domestic HIV/AIDS Epidemic," Open Society Institute

press release, May 23, 2006. Available at http://www.soros.org/initiatives/health/focus/phw/news/usreport_20060523.

109. Ibid.

110. Ibid.

111. Lou Chibbaro Jr., "100 Arrested in AIDS protest at US Capital," *New York Blade News*, May 28, 2004, 15.



PART 2

INTERNATIONAL POLITICS

