

# The Politics of Prevention: Lessons from the Neglected History of US HIV/AIDS Policy

Tasleem J. Padamsee  
The Ohio State University

**Abstract** The history of government action on HIV/AIDS has much to teach us about the dynamics and possibilities of US public health policy, but it has been insufficiently studied by social scientists of the epidemic. This article draws on a large set of original interviews with policy makers, thousands of news articles, and extensive documentation to reconstruct the history of three areas of debate and decision making about HIV prevention since 1990: needle exchange, HIV testing, and sex education for at-risk groups. These histories illuminate three key lessons. First, scientific evidence has less power to drive public health policy in the United States than in the United Kingdom, which is used as a comparison case to contextualize US choices within a broader range of options. Second, moral concerns weigh so heavily in the United States that a publicly articulated moral argument can countermand the dictates of solid scientific evidence, the voices of experts, and practical considerations to push public health policy in entirely oppositional directions. Third, having the ear of the presidential administration is usually a necessary—although not always sufficient—condition for the success of advocates trying to move US policy in the public health-indicated direction.

**Keywords** HIV/AIDS, public health policy, HIV prevention, needle exchange, HIV testing

This research was made possible by financial assistance from the Ruth Landes Memorial Research Fund, a program of The Reed Foundation; the National Science Foundation; and the Wellcome Trust. The author wishes to thank Gene Deerman, Anne Esacove, Chavella Pittman, Sandra Tanenbaum, Edna Viruell-Fuentes, and the anonymous reviewers for their helpful comments on prior drafts of this article.

*Journal of Health Politics, Policy and Law*, Vol. 42, No. 1, February 2017  
DOI 10.1215/03616878-3702782 © 2017 by Duke University Press

## Introduction

For the past thirty years, HIV/AIDS has presented governments with ever-changing challenges related to financing treatment, preventing new infections, driving research, minimizing stigma, and more. The choices nations make in response to these challenges have profound consequences: they help determine what we know about a deadly disease, whether and how we prevent it from spreading, who gets treatment, and how effective those treatments will be. The history of these decisions also offers important lessons for public health scholars and practitioners, sensitizing us to enduring patterns that will shape future national policy choices in—and beyond—the HIV/AIDS arena.

Despite all that this history has to teach us about the dynamics and possibilities of US public health policy, national-level government choices in response to HIV/AIDS have been insufficiently investigated. In the US context, the first decade of policy activity has been thoroughly studied by a small group of scholars who have provided detailed accounts of local, state, and national action during these early years, focusing largely on the gaps, delays, and failings of government responses. Our knowledge of the second and third decades of US policy response, however, is less complete. Social scientists have conducted important studies of individual debates and decisions, but have not yet attempted to characterize or explain the broader trajectory of HIV/AIDS-relevant policy making. Government reports, such as the Institute of Medicine's comprehensive examinations of US national capacity to increase HIV testing (2011) or options for public financing of HIV care (2005) document relevant pieces of policy history, although their focus is not on policy trends or how they evolve. High-quality investigative reports, such as Frontline's *The Age of AIDS* series (2006), consider some of the political dynamics that have shaped the pandemic as well. This article moves beyond these critical pieces of the puzzle, drawing on comprehensive and detailed original research that systematically reconstructs the history of US HIV/AIDS prevention policy debates and choices since 1989. It focuses on the key lessons this history offers about the limited conditions under which *scientific evidence* can drive public health policy, the powerful impact of *moral argument*, and the conditions under which *activists and advocacy groups* are able to push policy in the direction recommended by public health experts, or away from it.

In spite of dedicated efforts to establish a knowledge base from which the promotion of public health can proceed, policy in a controversial arena such as HIV/AIDS prevention rarely evolves smoothly in the direction indicated by public health experts. Such experts—practitioners and scholars

of public health—often assert a consensus about what I will refer to as the public health-indicated direction: the policy decisions that public health leaders agree would best promote public health. Such a consensus is most often articulated in terms of a strong base of relevant scientific evidence. Public health arguments about the advisable course for policy action, however, are not based solely in such scientific rationales. In cases where clear scientific evidence is not present, the public health-indicated direction can be heavily influenced by consensus judgments about what seems to work best in practical application. More important in the context of the history analyzed here is the fact that values-based convictions about what is ‘right’ (such as the value of protecting even socially marginalized groups from HIV, or the importance of keeping information about an individual’s HIV status private) also underlie many public health recommendations. This public health-indicated direction constitutes only the start of a policy-development conversation; which policies are actually implemented depends heavily on the political environment. This is particularly true in the United States, where a publicly articulated moral counterargument can outweigh even strong scientific evidence, and where policy only moves in the public health-indicated direction when organized proponents of that direction have the ear of the presidential administration. Analytically, the public health-indicated direction provides a conceptual starting point from which to understand the evolution of policy debate on a given topic, and a stationary point against which to compare resulting policy decisions. Moral argument is an important feature of HIV prevention debates in the United States, but not all types of moral argument are equally present in the field of play. The values-based concepts embedded in public health goals reflect the strand of moral argument James Morone (2003) refers to as social gospel discourse, but it remains largely in the background of US HIV/AIDS policy conversations. In contrast, moral counterarguments pushing against the public health-indicated direction represent a second, moralist strand of moral discourse organized around concepts of private vice and virtue (Morone 2003), and are strongly foregrounded in these debates.

Following a brief description of the range of data I employ, this article focuses on key illustrative episodes from three areas of HIV/AIDS-related debate and decision making since 1990: needle exchange, HIV testing, and sex education for at-risk groups.<sup>1</sup> These histories illuminate three key lessons about the political dynamics that constrain public health action in the United States. First, scientific evidence has only limited power to drive

1. Discussions of contemporary events are current through December 2015, when this article was accepted for publication.

public health policy in the United States. While strong research findings often drive experts and administrators to instigate new public health activity, the potential for these seeds to grow into fully implemented health policy is particularly constrained in the US context. Second, moral arguments about sexuality and drug use are a key feature of the political dynamics that forge US health policy. So heavy is the weight of moral concerns in this context that a publicly articulated moral argument can countermand the dictates of solid scientific evidence, the voices of experts, and practical considerations, to push public health policy in entirely oppositional directions.<sup>2</sup> As a result of both the comparatively weak impact of scientific argument and the comparatively strong impact of moral arguments mobilized to contradict science-based recommendations, US health policy often deviates dramatically from that of other nations facing similar public health challenges. Third, the process of revising public health policy is often driven by advocacy groups from outside of government, but their impact is largely determined by their degree of access to the presidential administration. With very few exceptions, having the ear of the administration is a necessary—although not sufficient—condition for the success of advocates trying to move policy in the public health-indicated direction. When either advocacy groups opposed to that policy direction have the ear of the administration, or a moral counterargument is publicly mounted, policy tends to move away from the measures advocated by public health experts.

## Data

I have reconstructed the largely uncatalogued history of US HIV/AIDS policy making since the late 1980s by drawing on three forms of data. First, I examined daily news data from the start of 1989 through 2013, including: (1) all *New York Times* articles containing joint references to ‘AIDS’ and ‘policy’ or ‘HIV’ and ‘policy’; (2) all articles pertaining to domestic policy in the Kaiser Daily HIV/AIDS Report;<sup>3</sup> and (3) the legislative histories of

2. Although the policy-shaping power of moralistic arguments about sexual behavior and drug use is particularly strong in the United States, other forms of values-based policy making do exist elsewhere. The European Union (EU) formally espouses the precautionary principle (Commission of the European Communities 2000), for instance, which has resulted in particularly restrictive regulations on genetically modified foods in Europe, despite a lack of clear scientific evidence that they pose health risks.

3. Produced by the Kaiser Family Foundation and searchable at [www.kaisernet.org/daily\\_reports/rep\\_hiv.cfm](http://www.kaisernet.org/daily_reports/rep_hiv.cfm). This report was terminated in September 2009; for the purposes of my data collection I replaced it starting that month with the Kaiser Health News Daily Health Policy Report ([www.kaiserhealthnews.org/Headlines.aspx](http://www.kaiserhealthnews.org/Headlines.aspx)), and the daily *POZ News Top Stories* ([www.poz.com/archive/currentNews\\_1.shtml](http://www.poz.com/archive/currentNews_1.shtml)).

all HIV/AIDS-related national proposals as listed in *Congressional Universe*. The resulting dataset includes more than twenty thousand daily, contemporaneous stories that provide a detailed view of unfolding policy processes, including not just legislative proposals that passed, but also those that failed, proposals that never drew legislative attention, undebated executive and regulatory actions, public protests, and advocates' attempts to raise issues to public attention. Second, I conducted seventy original, semi-structured interviews with policy makers and advocates who played key roles in decision making about US HIV/AIDS policy. Interviews were conducted in 2005 and 2010–2012; they averaged about one and a half hours in length; most were conducted in person, but some were done by phone. Most informants spoke confidentially and are thus cited below using unique identification numbers; several waived confidentiality and chose instead to be identified by name. Finally, the analysis draws on a wide range of documents that provide details of the policy-making dynamics at critical junctures in the history. These documents—many publicly available, but others I accessed only through my informants—come from both inside and outside of government, and include agency reports, hearing and debate transcripts, congressional and parliamentary testimony, executive orders, issue briefs, advocacy guides, and meeting notes.

This research on US prevention policy is one part of a larger project that also incorporates parallel data from the United Kingdom, including: daily news data from *The Guardian*, *The London Times*, *The Financial Times*, and *Parliament Publications Database*; fifty-five original, semi-structured key informant interviews with policy makers and advocates who contributed to HIV/AIDS policy decisions in the United Kingdom; and a range of governmental and advocacy documents from British sources. The following discussion draws occasionally on these comparative data to help contextualize US choices within a broader range of options.

### **The Battle over Needle Exchange: A Unique American Problem**

Needle exchange is an arena of HIV/AIDS prevention policy that clearly illustrates the inability of even strong, stable, and well-disseminated scientific evidence to drive US public health action in the face of a forcefully articulated moral counterargument. While both public health leaders and organized advocacy groups have campaigned intensely for federally sponsored needle exchange projects, this potentially powerful tool of HIV prevention has been repeatedly derailed over two and a half decades by a consistent set of morally based counterarguments. The history of needle

exchange also demonstrates the unusual salience of this problem in the United States, which has made dramatically different decisions than other Western nations faced with the same problem of HIV among injecting drug users. This contrast is demonstrated here through a comparison of needle exchange policy processes in the United States and the United Kingdom.

In the late 1980s, several Western countries became aware that injecting drug use was driving the HIV/AIDS epidemic in certain major cities (e.g., New York and Edinburgh). Significant proportions of users were already infected, and surveillance experts feared they might also transmit the virus to their sexual partners, thereby precipitating a significant epidemic among non-drug-using heterosexuals (Berridge 1998). During the preceding decade, drug treatment experts had developed new strategies (including methadone maintenance, substance abuse treatment, and needle exchange) that aimed to mitigate the damage to addicts' lives and guide them step-by-step toward sustainable improvements. Despite widespread expert agreement that these harm reduction methods would be more effective than the dominant, penal approach to drug abuse, however, they had not yet been embraced at the start of the HIV/AIDS epidemic (Berridge 1998). With the arrival of a deadly, transmissible virus on the scene, scientific experts and government commissions attested to existing evidence that providing users with clean needles would reduce HIV transmission without increasing drug abuse, highlighting needle exchange as a potentially critical prevention mechanism. Social conservatives in both the United States and the United Kingdom, however, objected that such programs would send a message that drug use was acceptable, and worse, that they would facilitate the illegal, unhealthy, and immoral use of drugs. It was after this point that policy discussions in the two nations diverged dramatically.

In the United Kingdom, the first official consideration of the issue came from the McClelland Committee,<sup>4</sup> which was tasked to investigate and report on the issue of drug abuse and HIV in Scotland. Composed of more than two dozen experts in the fields of HIV and drug abuse, the committee heard testimony from additional UK research and treatment experts as well as a prominent epidemiologist from San Francisco, reviewed published scientific evidence, and deliberated in topic-specific subcommittees. The committee's report, issued in late 1986, made recommendations based on scientific evidence and expert medical experience with both HIV and drug abuse. The twenty-four-page document made no reference to moral arguments or right and wrong, but focused on the twin public health goals

4. Officially, this was the Scottish Committee on HIV Infection and Intravenous Drug Misuse, which was subsequently known as the "McClelland Committee," after its chairman.

of minimizing both HIV transmission and drug abuse. Throughout, the report identified protecting the “general” population from HIV as a primary motivation for interventions to stem drug misuse and adopt harm minimization strategies. It opened,

In December 1985 reports of 2 studies in Edinburgh revealed a prevalence of Human Immunodeficiency Virus (HIV) antibody seropositivity in intravenous drug misusers which was considerably higher than that in many places in Europe and the United States. . . . This was a matter of concern in itself, but especially because the transmission of the virus by the sexual route from intravenous drug misusers could lead to wider spread of HIV infection into the general population, including individuals who are not in the previously recognized at-risk groups. (Scottish Home and Health Department 1986: 1)

Drawing on comparative evidence from other countries and consultations with UK practitioners, the Committee argued strongly that accommodations must be made to minimize the ramifications of injecting drug use for users who could not quit immediately, concluding that, “An exchange system [is] essential in an area like Edinburgh where there would be real risk that discarded needles would be infected” (Scottish Home and Health Department 1986: 11). Acknowledging the worry that needle exchange availability might increase the prevalence of drug abuse and the lack of scientific evidence necessary to rule out this possibility at the time, the Committee nonetheless articulated a careful argument that needle exchange made sense once the broader range of health risks to the entire population was considered: “Drug use occurs mainly among young people. They are sexually active and are likely to have sexual contact with partners who may well not be involved in drug misuse. . . . There is therefore an urgent need to contain the spread of HIV infection among drug misusers not only to limit the harm caused to drug misusers themselves but also to protect the health of the general public” (Scottish Home and Health Department 1986: 5).

As historians of the period have found, the UK Department of Health and Social Security (DHSS) acted on the strength of this prominent, specifically science-based recommendation to initiate several pilot needle exchanges, along with a monitoring program to assess their efficiency (Berridge 1998).<sup>5</sup> Meanwhile, the national Advisory Council on the Misuse of Drugs (ACMD) established a working group on AIDS and drugs misuse. Oral and written

5. Note that although the McClelland Committee investigation was strongly science based, the concluding recommendation quoted above also reflected a value judgment based on the hierarchy of needs concept, and that this conclusion exerted important influence on the development of UK HIV prevention policy.

evidence was provided to the group by more than seventy experts in drug misuse and AIDS, including physicians, psychiatrists, social workers, police officers, AIDS counselors, drug workers, and others. Pulling together scientific evidence, epidemiological studies, and the clinical observations of relevant practitioners, the group's culminating report strongly reiterated the recommendation to implement harm reduction programs in early 1988 (ACMD 1988). The report's "Overview" previewed its core argument: "The report's first conclusion is that *HIV is a greater threat to public and individual health than drug misuse*. The first goal of work with drug misusers must therefore be to prevent them from acquiring or transmitting the virus" (ACMD 1988: 1; emphasis in original).

Through multiple chapters that detailed scientific evidence and explored possible ways to address the relationship between drug abuse and HIV, the report detailed an argument that because "the spread of HIV is a greater danger to individual and public health than drug misuse . . . services which aim to minimize HIV risk behavior by all available means should take precedence in development plans" (ACMD 1988: 17). It was strongly recommended that these services consider a "hierarchy of goals" relevant to drug misusers, recognizing both the ultimate need to help individuals become drug free and the demonstrated reality that HIV could spread rapidly when needles were in short supply. The ACMD acknowledged that the ongoing pilot programs would provide better evidence about the effectiveness of needle exchange in preventing HIV and its impact on drug abuse, but argued that national action should nevertheless begin immediately: "the need for preventive action is urgent . . . our judgment is that the benefits of reduced sharing which will occur if needles and syringes are made readily available alongside health education will outweigh the risks involved in any increase in the injecting population which may result. . . . *We recommend that further exchange schemes be set up drawing on the experience of the more successful pilot projects*" (ACMD 1988: 41; emphasis in original).

The ACMD's report ignited several months of intense negotiation, most critically between DHSS, which was highly motivated to reduce the spread of HIV, and the Home Office, which favored tougher law enforcement against drug users (Street and Weale 1992; Berridge 1996). The decisive turning point came later the same year, when positive results from the needle exchange pilot programs were revealed. Given the Thatcher government's stated commitment to prioritizing HIV/AIDS as a public health issue, British leaders felt that the scientific consensus now obliged them to implement needle exchange at the national level (Berridge 1996). With the



conservative Tory government funding pilot studies to provide actionable scientific evidence and motivated by their concern about drug users as a bridge for HIV to affect the heterosexual community, harm reduction advocates won out quite quickly (Interviews with Aviva Bresky, Hilary Curtis, Graham Hart, and Informant 154; Stimson 1990). With the support of public health advisors and Health Minister David Mellor, nationally funded needle exchange programs were permanently authorized in 1988, and quickly instituted in areas with high numbers of injecting drug users (Street and Weale 1992; Berridge 1998). Of the fifteen policy makers with experience relevant to this policy-making episode who were interviewed, all focused on the role of scientific evidence in motivating the British government's action, and no mention was made of moral politics playing a role. They uniformly considered the nationwide implementation of needle exchange to have been one of the UK's most notable successes in the fight against HIV.

British politicians thus viewed the existence of a clear scientific consensus as locking them into a specific course of policy action. My historical research reveals, however, that their American counterparts saw the same science as merely one input into their decision.<sup>6</sup> United States public health experts of the 1980s agreed with those in the UK and other Western nations that a harm reduction approach held more potential to stem both the transmission of HIV and the use of illegal drugs than the penal framework of the US "War on Drugs." Powerful players within the Reagan administration disagreed on the issue, with Secretary of Health and Human Services Louis Sullivan sympathetic to needle exchange, but Director of the Office of National Drug Control Policy William Bennett and others pushing more effectively against harm reduction strategies (Zonana 1989). Congressional debates from this time offer insights into the rationales marshaled on both sides of the issue. The argument supporting needle exchange programs looked very much like that in the UK, citing and summarizing relevant scientific studies, and assembling a line of logic having to do with the ultimate goal of reducing drug use and the interim goal of harm reduction. In hearings before the Senate Committee on Governmental Affairs, a senior official from the National Institute of Drug Abuse explained,

Since AIDS cannot be cured as yet, prevention of the spread of the virus that causes it is imperative. The most effective way to prevent the spread of AIDS among intravenous drug abusers is for abusers to stop using

6. For a more general discussion of the distinctions between the roles of scientific expertise in American and European policy making, see Jasanoff 1998.

drugs . . . therefore, high priority must be given to intravenous drug abuse treatment, in order to help addicts discontinue their intravenous drug use. However, while helping addicts to quit using drugs intravenously or in any way, is our ultimate goal, many intravenous drug users will be unwilling to enter drug abuse treatment and will continue to inject drugs. . . . An effective AIDS prevention strategy must, therefore, go beyond a focus on drug abuse treatment alone. (Testimony of Dr. Roy W. Pickens, director of clinical research, NIDA; Committee on Governmental Affairs, June 6, 1988)

Another official added “for drug users who continue to inject, alternative approaches to reducing HIV transmission are to distribute bleach that IV drug users can use to clean their equipment and to exchange their used needles for sterile ones” (Dr. Jane Sisk, senior associate, Office of Technology Assessment; Committee on Governmental Affairs, June 6, 1988).

Lawmakers on the opposite side of the issue articulated an argument not about the effects needle exchange would likely have on rates of either HIV transmission or drug abuse, but about the need to advance the War on Drugs, and about the dangerous message needle exchange programs would send—that US society does not disapprove of drug abuse. Representative Charles Rangel of New York, for instance, remarked,

As chairman of the House Select Committee on Narcotics Abuse and Control, I remain convinced that the city of New York, and indeed the nation, should concentrate all of its manpower and financial resources toward preventing our citizens from even having a desire to try any illegal drugs. . . . An approach, such as the [clean needle] distribution program that has been proposed by the city of New York, represents not only a waste of manpower and financial resources, but also concedes defeat in . . . [the] “War on Drugs.” (Remarks of Representative Charles Rangel, New York, on the topic of Distributing Needles in New York City; Congressional Record, October 13, 1988)

In support of his position, Rangel cited an editorial from the *New York Daily News* “by providing needles on even a limited basis, the state—the government, society—would be saying ‘yes.’ We would be saying, in an unmistakable sense, that these killer substances are okay. That shooting up is at least understandable, acceptable. Government would be cooperating in narcotics use, by providing the means” (Cited by Representative Rangel; Congressional Record, October 13, 1988).

A week later, Rangel emphasized his position, noting, “I remain opposed to this plan because I believe that it will send to drug users a signal that their habits are acceptable to our society. Drug users, and perhaps more importantly, those who have considered, but never used drugs, will begin to believe that our society has demonstrated its support of the use of illegal drugs by supposedly making ‘shooting up’ safer. Nothing could be farther from the truth” (Remarks of Representative Rangel, *Congressional Record*, October 21, 1988), and citing another editorial highlighting the particular problem needle exchange poses to African American communities: “Even though AIDS has risen to become a giant killer among blacks, it has not cut nearly the path of damage that drugs have over the last 20 years. So any signal that seems to say ‘yes’ to drugs arouses the black community” (Cited by Representative Rangel; *Congressional Record*, October 21, 1988).

The evidence-based *scientific* argument that needle exchange programs would prevent HIV transmission thus lost out to a *moral* argument that such programs would cause damage to the public by softening the government’s disapproval of drug abuse. In stark contrast to the choice of other developed nations—from the Netherlands and the UK to Australia and New Zealand—to institutionalize needle exchange as a core HIV prevention strategy around 1988, the US Congress passed a unilateral ban on federal funding of needle exchange programs that same year (Zibbell 2003; Padamsee 2007; Gay Men’s Health Crisis 2009). In a minor concession to public health arguments, that law stipulated that the US Secretary of Health and Human Services (HHS) could rescind the ban if future research found: (1) that such programs reduced the spread of HIV; and (2) that they did not increase the prevalence of drug abuse (Health Omnibus Programs Extension of 1988, P.L. 100–607). This proviso would resurface as the focus of intense debate a decade later.

During the next few years, it became clearer than ever that injecting drug use was a major driver of the US epidemic (PACHA Meeting Minutes, December 1995). In a critical 1995 report, a panel of Institute of Medicine and National Research Council experts concluded that needle exchange had been proven to meet both criteria for lifting the federal funding ban, and officially endorsed it as a prevention strategy (Anderson 1991; Normand, Vlahov, and Moses 1995; PACHA Meeting Minutes, July 1995, September 1995, December 1996). Four years of intense political struggle followed, as HIV/AIDS advocates and organizations from AIDS Action to the Whitman Walker Clinic pushed hard for the United States to cut off a main transmission route for HIV by allowing federal funding for needle exchange,

and powerful conservative members of Congress insisted the nation stick to its “hard line” on drugs. This highly public battle exemplified the intense push-and-pull dynamic between the Republican-dominated Congress and the Democratic administration that shaped much HIV/AIDS policy during President Clinton’s second term. Arrayed in favor of rescinding the ban were the weight of scientific evidence and the prominent voices of AIDS activists, the surgeon general (David Satcher), leaders of the Centers for Disease Control (CDC), congressional Democrats, the Presidential Advisory Council on HIV/AIDS (PACHA), and the director of national AIDS policy (AIDS czar, Sandra Thurman); on the other side were those determined to preserve the ban, including Clinton’s drug czar (Barry R. McCaffrey) and socially conservative legislators (Interviews with Cornelius Baker, Kristine Gebbie, Gregg Gonsalves, Sandra Thurman, and Informants 5, 10, 20, 22, 27, 29, 30, 33; PACHA Meeting Minutes, September 1995–March 1998; PACHA Progress Reports: 7/8/96, 12/7/97; PACHA Letters to Secretary Shalala: 12/17/96, 3/16/98; PACHA Letters to President Clinton: 12/7/97, 3/17/98; Wren 1998). Closely echoing the debate of a decade before, defenders of needle exchange marshaled scientific evidence that it could save lives and even reduce drug use, while its opponents made a moral argument that needle exchange was antithetical to the War on Drugs because it both condoned and facilitated immoral, illicit drug use. Public opinion was split: people feared HIV, but needle exchange continued to resonate more as a drug control issue than an HIV-related one (PACHA Meeting Minutes, December 1995).

The minutes of PACHA meetings provide one detailed window onto the intensive political debate at play during these four years. Of the ten meetings of the full Presidential Advisory Council on HIV/AIDS convened during these years, nine included substantial attention to the needle exchange issue—and in several cases, this issue was a primary focus of the meeting (PACHA Meeting Minutes: July and December 1995; September and December 1996; April, July, and December 1997; March and June 1998). From just before the Institute of Medicine report was issued through the administration’s final decision in early 1998, each of these PACHA meetings noted that scientific evidence now strongly supported the desirability of needle exchange as a prevention method that could reduce HIV transmission without increasing drug abuse; this evidence was reviewed, cited, and summarized on multiple occasions. The council as a whole, as well as its research and prevention subcommittees, were actively involved in advocating for an end to the needle exchange ban on the basis of scientific arguments. Recognizing the opposition, PACHA discussions also

included notes, for instance, that the issue “needs to be taken out of a moral context” (PACHA Meeting Minutes, December 1995: 28). The council’s advocacy involved convening meetings with politicians, scientists at the National Institutes of Health, officials from the Office of National AIDS Policy (ONAP) and other government agencies, as well as issuing several formal recommendations and letters to President Clinton, Secretary of HHS Shalala, and the surgeon general. Through these means, PACHA pressured Secretary Shalala and President Clinton to certify the science on needle exchange and lift the ban, to position needle exchange to Congress as a public health issue, and to view needle exchange as essential to achieving their stated goal of reducing the US HIV transmission rate to zero. As these years wore on, ONAP officials began to report back to PACHA that although the administration was listening, the issue was becoming “problematic” and “political” (PACHA Meeting Minutes, July 1997: 4, 9). In July 1997, the Council minutes expressed “growing frustration about where this Administration is going and [noted] that needle exchange is a litmus test for its commitment to AIDS. . . . There is mounting evidence that some efforts by the CDC to provide scientifically based, innovative leadership have been thwarted by political indecision on the part of DHHS. This cannot continue if progress is to be made on the President’s [zero transmission] goal” (PACHA Meeting Minutes, July 1997: 4–9). Within the next year, PACHA became increasingly frustrated, with individual members and the council as a whole expressing (but not acting on) willingness to demand Secretary Shalala’s resignation, or to resign themselves over delays in administration action.

A consistent account of the arguments that shaped needle exchange policy in these years came from all thirty-five key informants who had possessed personal experience with these debates since 1995. Discussion in favor of needle exchange was heavily and specifically motivated by science (Interviews with Donna Crews, Scott Evertz, Sam Friedman, Jeffrey Levi, Matthew Murguia, Carl Schmid, and Informants 5, 20, 28, 29, 30, 133, 143, 157, 162). Informants described how they themselves, as well as other scholars, activists, public health leaders, and lobbyists cited specific scientific evidence and research summaries to articulate the case that needle exchange programs effectively prevent HIV transmission without increasing rates of drug abuse—and further, that these programs can actually help addicts *reduce* their drug use by drawing them into contact with other services (Interviews with Donna Crews and Informant 20). To the frustration of expert informants from both sides of the political spectrum, however, all this scientific argument seemed not to matter

(Interviews with Sandra Thurman and Informants 5, 20): the momentum toward federal funding for needle exchange was effectively derailed by an opposing argument from ideological conservatives that lifting the ban would be tantamount to condoning drug abuse (Interviews with Jeffrey Levi, Carl Schmid, Julie Scofield, and Informants 5, 6, 20, 102, 143, 157).

Meanwhile, African American leaders had not yet mobilized in support of HIV prevention within their own hard-hit communities (Cohen 1999) and many, including Charles Rangel (chairman of the Select Committee on Narcotics Abuse and Control) and other members of the Congressional Black Caucus, continued to voice fear that any relaxation of the official stance on drug abuse could be devastating to communities already struggling with drug problems (Interviews with Cornelius Baker, James Curran, and Informant 5). This concern further diluted support for needle exchange, as Congressional Black Caucus members sided with conservatives in their concerns about worsening drug abuse, rather than with the more liberal representatives who may have been willing to support a harm reduction approach (Informant 6).

The political contest was unpredictably tight until the last moments: on the eve of the decision “everybody [close to the administration] understood that the ban was going to be rescinded” (Interview with Kristine Gebbie). In the final hours, however, the president was apparently influenced by the drug czar (Interviews with Kristine Gebbie, Gregg Gonsalves, Sandra Thurman, and Informants 27, 29), and by the political concerns of congressional Democrats—who worried that an administration decision that could be interpreted to undermine the War on Drugs would jeopardize their future electability (Informant 8). In the spring of 1998, Secretary of Health and Human Services Donna Shalala announced that needle exchange programs had been proven effective, but that the ban on federal funding would nonetheless remain in place (Interviews with Kristine Gebbie, Gregg Gonsalves, Jeffrey Levi, and Informants 5, 6, 9, 10, 29; PACHA Meeting Minutes, December 1997; Health and Human Services Press Office 1998; Padamsee 2007). The reaction of HIV/AIDS experts was shocked and condemning:

The belated willingness to certify the scientific fact that needle exchange programs help reduce HIV infection without increasing drug use was an important step forward. However, the accompanying refusal to allow states and localities to use federal funds to support this successful intervention represents the triumph of political expediency over scientific evidence and compelling human need. . . . Your decision on this

matter simply accentuates the failure of your Administration (and the country as a whole) to take effective action to stem the twin epidemics of HIV and drug use in our country. (Letter from PACHA to President Clinton 9/16/98)

In a rare overt nod to the social gospel strand of moral argument based in concern for tolerance and justice, PACHA also listed continued advocacy for needle exchange in its next catalog of priorities under “Specific, Not Short-Term Achievable, But Morally Important Objectives” (PACHA Meeting Minutes, June 1998). Pragmatically, PACHA was concerned that the implications of the administration’s decision might be even more far-reaching, as “the issue [had] become ‘a symbol of politics, rather than science,’ driving policy” (PACHA Meeting Minutes, March 1998: 4–5, quote from Sandra Thurman).

For the next fourteen years, HIV/AIDS advocacy groups continued to push the issue with Congress and federal agencies, and legislative debates over needle exchange continued, but federal policy remained unchanged.<sup>7</sup> At the end of 2009, President Obama’s administration acted on the fifteen years of additional work HIV/AIDS policy advocates had done in educating members of Congress about needle exchange—and took advantage of the rare opportunity afforded by a Democratic administration, strong Democratic majorities in both houses of Congress, and a political agenda over-filled with a national recession and a broader debate over health care reform—to quietly lift the ban on federal funding of needle exchange with relatively minimal overt discussion (Interviews with Sandra Thurman and Informants 22, 102, 105, 143, 157). The CDC’s leaders cautiously generated guidelines for states that might wish to use their existing grants to fund needle exchanges, but—well aware by now that it would be safer to keep the issue under the political radar—mounted no explicit drive to encourage such uses (Informant 105). This long-awaited alignment of US policy with public health practice across the developed world represented a major triumph for advocates who had been working on the issue for twenty years, but it was short-lived. Only two years later, Congress reinstated the ban as part of the federal spending plan for 2012 after a short debate voicing the same themes that have always shaped the conflict between US needle exchange advocates and opponents (Interviews with

7. Because Congress must approve the District of Columbia’s annual budget, the city’s desire to implement needle exchange programs provided a prominent continuing venue for this debate at the federal level (CDC 2001; Kaiser Daily HIV/AIDS Report: 1/11/99, 7/29/99, 7/30/99, 9/30/99, 10/27/99, 10/29/99, 11/2/99, 11/3/99, 11/4/99, 11/19/99, 9/7/00, 9/7/01, 10/12/01, 11/8/01, 12/5/01, 7/26/02).

Jeffrey Levi, Carl Schmid, Julie Scofield, and Informants 22, 162; Barr 2011). Despite the relatively back-burner status of this issue in the contemporary political landscape, then, the fate of federal funding for needle exchange continues to depend on the balance of partisan control in Congress.

The long-term absence of federal help has motivated harm reduction advocates to take up the fight at more local levels. More than half the states and many heavily affected cities have been convinced of the need to provide clean needles, passing statutes allowing needle exchange and using their own tax funds or private financing to establish local programs (Guardino et al. 2010; AVERT 2012; NASEN 2012). Nevertheless, the piecemeal and vulnerable nature of these efforts has meant that these resources are substantially less available in the United States than elsewhere. Unlike in the UK, thousands of injecting drug users are still infected with HIV in the United States each year, there are still vastly fewer drug rehabilitation openings than users seeking help, and the criminalizing “War on Drugs” discourse still dominates the landscape. Scholars generally believe—although it is hard to demonstrate a definitive causal relationship—that this gap in US prevention efforts has resulted in higher HIV infection rates among injecting drug users in this country—where prevalence is upwards of 15 percent—than others such as the UK—where prevalence is less than 3 percent (Mathers et al. 2008). When asked to reflect on the best and the worst of US HIV/AIDS policy history, many US key informants listed the long-term federal ban on needle exchange funding as one of its lowest points (Interviews with Matthew Murguia, Sandra Thurman, and Informant 133).

In the case of needle exchange, the United States and the United Kingdom faced the same problem, proposed solution, and basic arguments—yet the two countries made very distinct policy decisions. The UK institutionalized needle exchange early on, a decision widely credited both with saving thousands of lives and with rendering injection drug use an irrelevant factor in the national spread of HIV. The United States outlawed such programs in the same year, setting the stage for decades of political debate in spite of ongoing infections among drug users and unilateral scientific support for needle exchange. The critical dynamic driving the unique and insistent American determination *not* to adopt a harm reduction approach to the problems of drugs and HIV has been the marginalized role of science in a highly politicized process of public health policy making. In 1988, 1998, and 2011, the US government repeatedly treated strong research results as merely one type of argument—parallel to and able to be countered by moralistic ones. Despite the repeated efforts of advocacy groups and public



health leaders, strong conservative resistance to “condoning” immoral drug use has driven policy decisions that continue to marginalize harm reduction in general, and to incapacitate needle exchange specifically (Interviews with Informants 5, 20, 30). In the UK, the moral argument against the personal vice of drug abuse has not been marshaled to resist the scientifically indicated policy in favor of needle exchange. More than the UK and other developed nations, the United States is a place where scientific evidence can be overridden by moral counterarguments, and where public health considerations can consistently fail to drive health policy decisions.

### **HIV Testing: Medical Exception or Health Care Routine?**

Just as strong scientific evidence has long supported the use of needle exchange for HIV prevention, scientific evidence at several junctures clearly supported particular HIV testing policies. Unlike in the case of needle exchange, however, moral counterarguments to these public health recommendations have never been mounted. The evolution of US HIV testing policy thus offers a stark contrast to the history of needle exchange policy. Although it was sometimes slowed by the concerns of advocacy groups and often negotiated through intense political debate, US HIV testing policy has never really detoured from the approaches indicated by the public health expertise of the time, instead creeping consistently forward in keeping with available scientific evidence.

Testing for HIV has been a key tenet of US national prevention policy ever since the first antibody test became available. It has been viewed as a multipurpose mechanism for locating HIV-positive individuals; connecting them to support, treatment, and information about how to avoid transmitting the virus to others; rendering them less biologically infectious; empowering those who test negative to remain so; and reducing the stigma surrounding HIV/AIDS. Initially implemented to screen donated blood in 1985, HIV testing also began immediately at Alternative Testing Sites, funded by the CDC to prevent at-risk individuals from donating blood as a way to access free HIV tests (Interviews with Informants 11, 32; Shilts 1987; Quam and Ford 1990; Ernst 1994). These sites initiated a long-lasting parallel structure for HIV testing through which some tests were given by health care providers, but most took place in community-based settings organized by AIDS service organizations and state health departments.

The initial development of a test for HIV status ignited intense debate about who should be tested, and how. This early battle exemplifies the importance of policy advocates on both the left and right ends of the

political spectrum in pushing for testing policies consistent with their own perspectives on the epidemic. Conservative politicians had advocated “contain-and-control” strategies since the start of the epidemic, so activists based in gay community groups and nascent AIDS service organizations feared the test would be used to single out HIV-positive individuals for coercive treatment (Shilts 1987; Quam and Ford 1990). Indeed, as soon as a test became available, conservatives proposed mandatory testing of high-risk groups, arguing that identifying HIV-positive individuals would enable others to avoid dangerous forms of contact with them, and thus HIV infection. They pushed hard for these policies—first in the legislatures of hard-hit states such as New York and California, and soon after at the federal level (Interviews with Informants 5, 133). But HIV/AIDS activists resisted vociferously, mobilizing both civil rights and public health arguments to prevent HIV testing from adding to the burdens of stigma and discrimination already faced by people with (and perceived to be at risk of) HIV (Interview with Bernard Branson; Brandt 1988; Bayer and Kirp 1992a; Krieger and Appleman 1994). At the height of this conflict, some activists even encouraged individuals *not* to be tested: in the context of calls for punitive HIV/AIDS policies and no effective medical treatment, the risks of confirming one’s status could be seen to outweigh the benefits (Interview with Informant 5).

Throughout the 1980s, testing policy remained on the front burner of HIV/AIDS politics. Public health officials and physicians worked together with activists to insist on a broad, liberal approach to HIV/AIDS policy with voluntary testing at the core. The weight of scientific expertise came to support their position in 1986, when both Surgeon General C. Everett Koop and the esteemed National Academy of Science/Institute of Medicine issued independent and highly publicized reports that pressured the federal government to act on HIV/AIDS. Both reports rejected compulsory measures and called instead for expanded voluntary testing along with guarantees of confidentiality and nondiscrimination (Institute of Medicine and National Academy of Sciences 1986; Koop 1986; Weiss and Thier 1988). The most persuasive argument emerging from this liberal coalition was that coercive measures were inimical to prevention goals because they would drive the individuals at highest risk underground, away from educational services that would prevent them from spreading the infection further (Bayer 2000; Harrington 2002). The IOM report argued that mandatory screening of selected high-risk populations raised serious ethical and feasibility problems, discriminating against or coercing entire groups without justification. Its recommendations emphasized that the “active

voluntary cooperation of individuals who are at risk will be needed to curtail the epidemic. Coercive measures will not solicit this cooperation and could prevent it . . . the committee recommends that public health authorities use the least-restrictive measures commensurate with the goal of controlling the spread of infection” (Institute of Medicine and National Academy of Sciences 1986: 15–16). The Surgeon General’s report further assured the American public that

Compulsory blood testing of individuals is not necessary. The procedure could be unmanageable and cost prohibitive. It can be expected that many who *test* negatively might actually be positive due to *recent* exposure to the AIDS virus and give a false sense of security to the individual and his/her sexual partners concerning necessary protective behavior. The prevention behavior described in this report, if adopted, will protect the American public and contain the AIDS epidemic. Voluntary testing will be available to those who have been involved in high risk behavior. (Koop 1986: 33; emphasis in original)

Based on a combination of scientific evidence and ethical argument, this position has had a lasting legacy, continuing to shape policy debates in the HIV testing arena for decades (Obermeyer and Osborn 2007).

The concept of mandatory testing was firmly rejected during the next two years, as US policy coalesced around this voluntarist philosophy. The CDC guidelines issued in 1986 and 1987 helped institutionalize it, encouraging increased testing by clarifying the “personal, medical, and public health benefits,” specifying counseling procedures to accompany the test, and insisting on procedures to ensure confidentiality and nondiscrimination because, “Persons are more likely to participate . . . if they believe they will not experience negative consequences” (CDC 1987: 155). Federal legislators including Democrat Henry Waxman and Republican Orrin Hatch drafted and debated bills designed to protect confidentiality and prevent testing-associated discrimination (Interviews with Nancy Taylor and Informant 6). Further, HIV prevention concerns also contributed to the passage of nondiscrimination legislation protecting the rights of people with HIV or AIDS, as well as those perceived to be at risk (Stine 1993; Adam-Smith and Goss 1997). Specific informed consent requirements for HIV tests were soon written into law in many states, often in response to instances of discrimination or abuse (Interview with Informant 143). By the end of the decade, then, fierce political debates over testing were largely settled in favor of the voluntary approach public health experts preferred, and HIV exceptionalism was firmly established through separate

testing sites as well as unique counseling and consent procedures. Conservative activists had attempted to create a more punitive and isolating response to the epidemic through testing policy, but never mounted the kind of morally based argument that might have counterbalanced scientific and expert pressures for a voluntarist public health approach.

In the testing arena, the 1990s was a decade of policy stability. Counseling and testing remained a significant focus of CDC expenditure, and new guidance aimed mostly to hone existing procedures by ensuring strict confidentiality; tailoring prevention messages, risk-reduction plans, and testing practices for specific regions and subgroups; and reducing barriers to clients returning for post-test counseling and results (CDC 1993, 1994; Interviews with Julie Scofield, Jeffrey Levi, and Christine Lubinski). This quiescence was also reflected in the fact that PACHA meetings included not a single discussion of any policy conversation relevant to HIV testing during its first nineteen meetings, from June 1995 through March 2002 (PACHA Meeting Minutes, 1995–2002). With only two exceptions, occasional conservative calls for mandatory testing of specific groups were quickly silenced by the more influential voices of public health experts and HIV/AIDS activists well integrated into the Clinton administration. The first exception involved federal prison inmates incarcerated for over six months, who became subject to mandatory testing with little organized opposition in 1998 (Interview with Informant 105). The second exception, and the only area of heated debate over testing policy during this decade, involved pregnant women.

In late 1994, a study widely known as ACTG 076 demonstrated that it was possible to prevent most mother-to-child HIV transmission through the administration of azidothymidine (AZT) during pregnancy (Connor et al. 1994; Kolata 1994). In response to this finding, the CDC recommended “*routine* HIV counseling and voluntary testing for all pregnant women” (CDC 1995: 2, emphasis added) emphasizing the counseling, consent, and confidentiality precautions delineated earlier, but encouraging a push toward systematic voluntary testing of every pregnant woman, and even recommending that HIV tests be offered to women of child-bearing age who were not pregnant (CDC 1995). In Congress, however, the ACTG 076 study findings also reignited the political battle of the prior decade. Conservatives now lobbied strongly for *mandatory* testing of pregnant women and newborn babies, pointing to the tragic and unacceptable nature of HIV infections among babies (Interviews with David Harvey and Informant 12). Other AIDS advocacy groups supported the push to prevent infant infections, but strongly opposed a mandatory testing

approach to achieving this objective. In addition to concerns that coercive testing risked driving pregnant women away from medical services or set the stage for punitive treatment of infected mothers, feminist groups and their congressional allies criticized mandatory testing policy for treating women as incapable of making decisions for their fetuses, and as mere vectors of disease—forcibly tested to protect their children, but provided with no guarantee of protection or treatment if they found themselves diagnosed with a stigmatized and deadly disease (Interviews with David Harvey, Christine Lubinski, and Informants 2, 6). They argued instead for policy mechanisms that would create routine but voluntary HIV testing among pregnant women, and that testing should be embedded in methods that would provide a broader range of needed services to vulnerable women and their families (Interviews with David Harvey, Sandra Thurman, and Informants 2, 105).

In 1995, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, which had been enacted in 1990 to finance medical care and support services for uninsured people living with HIV, came up for reauthorization. In this context, a highly polarized conflict ensued between AIDS activists opposed to mandatory testing and conservatives—led by Senators Jesse Helms, Newt Gingrich, and Bob Dole—who aimed to institute mandatory testing of pregnant women as a provision of the reauthorized CARE Act. The debate involved multiple rounds of competing amendments and the threat of a presidential veto, and ultimately delayed the reauthorization until mid-1996. The bill President Clinton eventually signed included a compromise agreement to develop guidelines to get pregnant women tested, but no specific decision on the policy question. The same heated debate was reenacted at the next reauthorization juncture in 2000, ending with a decision to routinize HIV counseling and recommend testing for all pregnant women, as well as all newborns whose mother's status was unknown. Several years later, funding was actually appropriated to support these interventions in the “Baby AIDS” problem (Interviews with Informants 2, 6; Kaiser Daily HIV/AIDS Report 10/14/98, 10/21/98; Leary 1998). The approach advocated by public health experts and HIV/AIDS activists—to encourage all pregnant women to be tested while keeping that decision voluntary—thus consistently won out, although conservatives continued to push the concept of mandatory testing instead.

The scientific, regulatory, and legislative processes that pushed toward regular testing of pregnant women during the late 1990s foreshadowed a more dramatic transition toward *routine HIV screening* of all groups in the following decade. The roots of this change date as far back as 1992, when

the CDC urged voluntary, routine testing of all young and middle-aged hospital patients in areas with an HIV prevalence of 1 percent or higher (Branson et al. 2006). This recommendation was largely ignored, due both to the specialized counseling and consent procedures required to test, and to the perception of HIV as a disease to be dealt with through separate structures (Interview with Bernard Branson). Nevertheless, the introduction of “routine testing” language with respect to patients in high-prevalence areas in 1992 and again with respect to pregnant women in 1994 represented subtle but critical shifts in the public health-indicated direction. In reaction to the best contemporary scientific information, CDC leaders during the 1990s began articulating a recommendation to move from *voluntary* (for those seeking it) testing to *routine* (optional but part of regular medical practice) testing for particular groups (CDC 1994, 1995; DeCock and Johnson 1998). As the decade wore on, public health leaders increasingly perceived the need to make HIV testing less exceptional, but the definitive push toward routinization did not come until around 2000.

By this point, it was becoming clear just how effective the Highly Active Anti-Retroviral Therapy (HAART) regimens launched in 1997 were. Indeed, HAART’s capacity to improve the health of persons with HIV disease, as well as its secondary effect of dramatically reducing their likelihood of infecting others, provided powerful rationales to improve the proportion of HIV-positive people who knew their status. The logic of the argument spread increasingly widely: most people don’t want to transmit disease, and in the era of HAART most of the people dying of AIDS were undiagnosed, so identifying all HIV-positive people was a critical piece of the prevention puzzle (Interviews with James Curran, Shannon Hader, Matthew Murguia and Informants 105, 129). The FDA’s approval of the first Rapid Test in 2002 was a crucial step, and came only after organized efforts by CDC testing experts, political support from the Bush administration, and substantial advocacy work by PACHA overcame the influential objections of clinical laboratories who had a vested interest in the existing system of HIV testing. Rapid testing made it possible for patients to take an HIV test and receive the results within a single emergency room visit, thus removing an important barrier to testing in health care settings (Interviews with Bernard Branson, James Driscoll, Shannon Hader, Neal Nathanson, Carl Schmid, Julie Scofield, and Informants 10, 31, 33, 58; PACHA Meeting Minutes, June 2002, November 2004, February 2005). The CDC ramped up prevention work with HIV-positive people through its Serostatus Approach to Fighting the HIV Epidemic (2001) and Advancing HIV Prevention

(2003) initiatives, which aimed to diagnose all those infected by working with professional associations and other partners to make HIV testing a more regular part of medical care (Janssen et al. 2001; CDC 2003; Interviews with Bernard Branson and Harold Jaffe; PACHA Meeting Minutes, August 2003).

Testing pregnant women for HIV continued to be the vanguard of the routinization discussion during the early 2000s: scientific reports documented hundreds of babies still being born with HIV each year despite increases in prenatal testing, and the CDC issued ever stronger recommendations for voluntary but regular testing during pregnancy (CDC 2001). This momentum culminated in 2003, when the CDC issued guidance that physicians should screen *all* pregnant women by including HIV in the routine battery of blood tests women authorize through a general consent to medical treatment (PACHA Meeting Minutes, June 2002; CDC 2003). This guidance introduced our contemporary form of routine testing for the first time—still voluntary, but in which patients are informed of the expected HIV test rather than asked if they would like to take it, and can “opt out” if they so choose, instead of needing to “opt in” to an HIV test specifically.

At the same time, CDC leaders began work on a new set of recommendations that would integrate HIV testing into the normal routines of medical care for all patients, convening consultations on draft language and gathering support from a range of stakeholders (Interview with Bernard Branson). Federally sponsored demonstration projects located significant percentages of previously undiagnosed HIV cases by testing in emergency departments; and showed that while some physicians resisted routine testing, patients generally accepted it (Heffelfinger et al. 2008). Between 2003 and 2005, HIV clinicians, public health experts (including New York City Health commissioner Tom Frieden), and health economists all wrote editorials arguing that HIV testing should be routinized (Interview with Bernard Branson; Frieden et al. 2005); more would follow (Koo et al. 2006). In 2005, two cost-effectiveness studies by respected researchers demonstrated that the cost of routine testing of all adults was outweighed by the savings introduced by reducing the number of new cases and starting infected persons on treatment early enough for it to be effective (Paltiel et al. 2005; Sanders et al. 2005). By now, most constituencies were on board: the Bush administration and the leaders of PACHA supported routinized testing for its prevention value; clinicians hoped routinization would stem the flow of very ill undiagnosed patients who should have been on treatment long before; prominent African American and Latino leaders hoped making

HIV testing a routine event would help destigmatize it in their communities; and Congress built incentives to routinize testing into the 2005 CARE Act reauthorization (Interviews with Bernard Branson, Harold Jaffe, and Informants 31, 102). The sole organized opposition came from some well-established HIV/AIDS advocacy groups, motivated in part by their vested interest in the existing counseling and testing system, but largely by longstanding fears of the potential for stigma or discrimination that might result without specialized consent and confidentiality procedures in place (Interviews with Bronwen Lichtenstein and Informants 6, 31). This resistance represents one situation where constraints on policy movement in the public health-indicated direction have come not from social conservatives, but from organized liberal groups.

The CDC published its official guidelines for routine HIV testing in 2006, recommending that adults and adolescents in all health care settings be tested for HIV at least once, and that those engaging in risk behaviors be tested annually (Branson et al. 2006). In addition to declaring HIV tests relevant to all Americans for the first time, the CDC simultaneously made them part of regular medical care by dropping requirements for specific written consent and counseling procedures before every test. These changes have continued to be controversial, particularly in the context of the policy changes some states (such as New York and Massachusetts) had to undertake in order to remove legal consent and counseling requirements before implementing the new guidelines (Informants 140, 141).<sup>8</sup> Nevertheless, concerted government efforts have continued to build support for routinization: Congress appropriated extra funding to support additional testing in the most severely affected jurisdictions; the CDC and HHS provided technical assistance to states preparing for the changes, coordinated data, monitored legislative changes and adoption of the new guidelines, and developed implementation guidance for specific settings (such as correctional facilities and STD clinics) (Interviews with Bernard Branson, Kathie Hiers, and Informant 149). Legal changes were required to compel insurance companies to cover HIV testing as a routine procedure (Interviews

8. The separate but related question of what types of HIV tests should be in use has also continued to be controversial since the CDC's 2006 routine testing recommendations. After the FDA approved the first Rapid Test in 2002, the locus of this controversy shifted to home test kits. Eventually approved in 2012 with widespread support (Horn 2012; McNeil 2012), home HIV tests had been the subject of years of argument. In favor of home tests, CDC experts and test developers argued that they could help reduce the number of infected individuals who did not know their status. Against them were arrayed clinical laboratories whose businesses could be damaged by home testing, and some community-based HIV/AIDS organizations – likely motivated by a combination of their vested interest in their role as alternative testing sites, and concern for the well-being of those who would be tested without counseling (The Body 2004; Millenson 2006).



with Jeffrey Levi, Gregory Pappas, Andrea Weddle, and Informant 129); CDC and other public health organizations have worked to decrease stigma and increase routine testing uptake by physicians and communities (Interviews with Cornelius Baker, Shannon Hader, Bronwen Lichtenstein, Gregory Pappas, Andrea Weddle, and Informant 21); and policies such as the 2010 National HIV/AIDS Strategy reflect the priority on routine testing (Interviews with Gregory Pappas, Carl Schmid, Wendy Wertheimer, Jack Whitescarver, and Informant 42). Largely distanced from national political debate, implementation of the new policy direction is still in progress, but has continued throughout the Obama administration. Research now shows substantial increases in testing across the country, and improving acceptance rates for routine screening (CDC 2008; Interviews with Brian Hujdich and Gregory Pappas).

The past six years, then, have seen a radical change in medical practice: HIV is now treated less as an exceptional disease than as ‘just another medical condition’ (Interview with David Harvey; Perez-Pena 2006). The transition to routine HIV testing, like the prior policy decision to encourage voluntary and protected testing of high-risk groups, was driven primarily by the weight of scientific evidence and the opinions of public health experts. During the first two decades of the epidemic, prominent conservatives advocating mandatory testing resisted the development of voluntary testing procedures, while HIV/AIDS activists on the left encouraged it. During the third decade, the recommendations of public health leaders evolved in the direction of routine (but still voluntary) testing for all groups as a result of medical and scientific discoveries. The ground under activists on both sides of the political spectrum now shifted. Routinization was uncomfortable territory for HIV/AIDS activists and service organizations with a long history of protecting those at risk of the disease by institutionalizing extra cautions around HIV testing, but easily espoused by conservatives as the intellectual descendant of the mandatory testing concept they had long supported. While some traditional HIV/AIDS issue advocates resisted the new policy direction, the social and religious conservatives influential within the Bush administration—in Congress, the Office of National AIDS Policy, PACHA, and HHS—helped to accelerate the shift to routine testing favored by public health experts after 2000 (Interviews with Bernard Branson, Shannon Hader, Andrea Weddle, and Informants 102, 134). For all the ways various stakeholders hampered and facilitated movement in the public health-indicated direction, though, that is the single direction in which HIV testing policy has always moved. Interview data from all forty-nine key informants with knowledge of HIV testing

issues uniformly supports the consistent focus of stakeholders (on all sides of testing debates) on scientifically supported methods of decreasing transmission, morbidity, and mortality, and on addressing discrimination and other impediments to achieving these public health aims. Without the persuasive power of moral arguments that pushed in contradictory directions, the story of HIV testing in the United States unfolded very differently from that of needle exchange, consistently following the lead of science.

Absent the unique American dynamic of effective moral counterargument, the United States has been much better aligned with the UK on policies regulating HIV testing than needle exchange. During the first stage of policy development, British deliberations followed an independent but parallel path that yielded a very similar, voluntarist approach to HIV testing. Motivated by determination to protect the uninfected population, British policy moved in 1984 and early 1985 toward declaring HIV a notifiable disease—a step that would have generated the same risks of isolation and discrimination as mandatory testing in the United States—but settled by the end of 1985 on a more liberal approach involving voluntary, confidential testing in health care and community settings (Berridge 1996). In the last few years, the second phase of UK testing policy has overtly followed the US lead, building on the same epidemiological research as the CDC to begin routine testing within the population subgroups most at risk for HIV infection (Informant 112). In both countries and both eras, then, scientific knowledge about HIV diagnosis, testing, and treatment has been the consistent driver of HIV testing policy.

### **Protecting the Public: Restrictive or Comprehensive Sex Education?**

The front line of HIV prevention throughout the US epidemic—teaching Americans how to avoid transmission through sex—has also been the most complicated arena for public health policy. Continually buffeted by both scientific and moral arguments but consistently driven by neither, US sex education policy has flip-flopped dramatically, from periods of intense restrictiveness to periods of comprehensive and candid approaches to educating the public about sexuality and HIV risk. The critical driver of these decisions has been the role of HIV/AIDS policy advocates, particularly those groups with the ear of the presidential administration of the time. The resulting fluctuations in federal policy have had profound effects on the prevention work that takes place around the country, because the CDC and other federal agencies fund the largest fraction of the nation's prevention

education programs, and because public health leaders at the CDC research, design, and disseminate educational materials that are used not only by organizations that receive federal funding, but also by many that do not (Interview with Informant 102).

Sex education programs for HIV prevention were launched by gay men's organizations in the first years of the epidemic. Often formed as local political organizations during the 1970s, many gay rights groups transformed themselves into service organizations in the early 1980s, providing food, transportation, physical assistance, and emotional support to growing numbers of sick and dying young men. The earliest safer sex advice emerged from these networks within a year after the first cases were announced in June 1981. It quickly became obvious that both anal sex and a high number of sexual partners were risk factors, and the self-initiated educational programs of urban gay communities yielded significant reductions in both behaviors by 1982 (King 1993). Communicating sex-positive messages, using frank language about specific sexual practices, and oriented toward changing individual behavior by transforming community norms, these programs were exemplified by Richard Berkowitz and Michael Callen's 1983 brochure, *How to Have Sex in an Epidemic*. Predating basic scientific knowledge about HIV, this publication nevertheless pioneered the "safer sex" model that recognizes the importance of sexual expression and aims for interventions that can dramatically reduce risk without requiring drastic changes in individuals' life choices (Interview with Ford Hickson; King 1993). These first, straightforward, community-based prevention programs were remarkably effective—curtailing infection rates among gay men within the first three years of the epidemic (King 1993)—and they constituted the first "best practice" models in the eyes of public health leaders.

As historians of the early epidemic have chronicled, the CDC quietly made its first small allocations to help community organizations fund their HIV prevention work in 1984 (Interview with Jeffrey Levi; Shilts 1987). The agency also attempted to launch its own education initiatives for gay men, but in 1985 stopped spending on these programs under orders from Ronald Reagan's White House, which maintained that, "the government should not be in the business of telling homosexuals how to have sodomy" (Shilts 1987: 576). Even after the CDC returned to routing its prevention efforts for gay men through intermediaries, the administration severely limited its funding for this highest-risk group: only \$250,000 (out of an HIV prevention budget of over \$60 million) went to gay men's education

through the US Conference of Mayors in 1986 (Bayer and Kirp 1992b; Poirier 1993; Holtgrave and Kates 2007).

This strategy of simply avoiding HIV prevention work was confronted by a serious challenge from the reports issued by the Surgeon General and Institute of Medicine (IOM) in 1986. Both reports advocated strong investment in comprehensive population education about how to prevent HIV transmission, and specifically countered conservative moves to block candid and pragmatic communication about sex. The IOM summarized,

The committee recommends a major educational campaign to reduce the spread of HIV. If an educational campaign is to change behavior that spreads HIV infection, . . . its message must be as direct as possible. Educators must . . . be willing to use whatever vernacular is required for that message to be understood. Admonitions to avoid “intimate bodily contact” and the “exchange of bodily fluid” convey at best only a vague message. Condoms have been shown under laboratory conditions to obstruct passage of HIV. . . . Young people, early in their sexually active lives and thus less likely to have been infected with HIV, have the most protection to gain from the use of condoms. (Institute of Medicine and National Academy of Sciences 1986: 10)

Both reports focused particularly on the educational needs of young people.

Adolescents and pre-adolescents are those whose behavior we wish to especially influence because of their vulnerability when they are exploring their own sexuality (heterosexual and homosexual). . . . Teenagers often consider themselves immortal, and these young people may be putting themselves at great risk. Education about AIDS should start in early elementary school and at home so that children can grow up knowing the behavior to avoid to protect themselves from exposure to the AIDS virus. . . . Those of us who are parents, educators, and community leaders, indeed all adults, cannot disregard this responsibility to educate our young. The need is critical and the price of neglect is high. (Koop 1986: 4–5)

In response, the CDC now began to bolster critical HIV/AIDS prevention work among high-risk populations through significant grants to community-based organizations and state health departments (Quam and Ford 1990). These programs soon drew the attention of social conservatives, however, and the candid, pro-sex approaches that had been proven effective by gay men’s health educators came under federal attack from the religious right and the US Congress. The resulting legislative activities

reached their peak with the ‘Helms Amendment.’ Outraged by sex-positive publications he perceived as “homeroetic literature,” Senator Jesse Helms amended the 1988 appropriations bill to prohibit federal funding of materials that would “promote or encourage, directly or indirectly, homosexual sexual activities,” and to require prevention programs to emphasize abstinence from extra-marital sex and illegal drugs (Helms 1987). These were strictly moral arguments, effectively mobilized to curtail the types of educational activity public health experts believed most useful in stemming the spread of HIV. The CDC was now compelled to institute strict guidelines for programs funded through its grants, and organizations that relied on federal financing to meet the ever-growing need for prevention work had to comply. Reluctant health educators made their messages about sex and drugs more vague, removed pictures of genitals and sexual acts, and revised their language to omit references to sexual orientation and anal sex (Ron and Rogers 1989; Quam and Ford 1990; King 1993; Ernst 1994; Allen 2000). Widely understood to disallow the use of proven HIV prevention methods, the Helms Amendment nonetheless remained in place until several years of legal action by HIV/AIDS activists resulted in its being overturned in federal court in 1992 (Allen 2000; Informant 22).

With the 1993 arrival of the first Democratic administration of the epidemic came a sudden increase in the power of the nation’s strongest HIV/AIDS issue advocates to influence policy. During the first decade of the epidemic, individuals with extensive professional and personal knowledge of HIV/AIDS had worked their way into policy-making conversations at the CDC, NIH, and FDA (Epstein 1996). They had exerted considerable influence on several prominent House and Senate members interested in HIV/AIDS as well, but had been unable to control the larger national agenda on the issue within the context of a Congress and presidency controlled by conservatives. My historical research demonstrates that they now gained access to agenda-setting influence at the highest levels of the executive branch. Both HIV/AIDS activists and leaders of AIDS service organizations worked on President Clinton’s campaign; these personal connections meant that the advocacy community had the ear of the White House from the start, and their improved ability to make their suggestions heard lasted throughout the administration (Interview with Sandra Thurman). In addition, doctors, public health officials, and activists steeped in the intricacies of the epidemic were now appointed to official positions in the new Office of National AIDS Policy and the Presidential Advisory Council on HIV/AIDS (PACHA 2000).

Unlike the conservative religious leaders who held so much sway with the Reagan and G. H. W. Bush administrations, these newly empowered advisors were strong proponents of comprehensive sex education for HIV prevention. As a result of their influence, federally funded efforts now expanded to include many of the sex-positive, candid, community-based programs favored by public health experts, as well as increased attention to sexually transmitted illnesses and condom distribution in high schools and colleges (PACHA Meeting Minutes, 1995–2000; Interviews with Kristine Gebbie, Julie Scofield, and Informants 6, 29, 32). The Presidential Advisory Council (PACHA) provided one strong pathway for this influence, both pressuring and supporting the president and federal agencies on issues including the development of public service announcements for high-risk populations, maintaining direct funding to community-based organizations, and “making HIV education in schools a priority” (PACHA Meeting Minutes, July 1995, December 1995, December 1996). President Clinton’s first Director of National AIDS Policy commented on prioritizing comprehensive sex education for children: “Not that I want teenagers to have sex, but if they are going to, I want them to know how to protect themselves. Not that I think anybody should do drugs, but if you are going to be hooked on injecting drugs, at least do it cleanly. Give . . . yourself a chance to live long enough, so that we can help you deal better with your life, get rid of the problems” (Interview with Kristine Gebbie).

After the mid-term elections that same year, however, the conservatives who took control of Congress fought to back away from the comprehensive education approach, and the next several years of HIV prevention reflected their repeated conflicts with the Clinton administration. In 1995, for example, the Senate stripped prevention funds from some organizations with controversial programs, and the American Red Cross toned down the candid language of its HIV prevention materials (Berke 1995; Kaiser Daily HIV/AIDS Report: 7/31/95). The hard work of HIV/AIDS advocates trying to resist these moves could often be seen in PACHA’s activities, which included substantial support for the CDC’s strategic plan for comprehensive sex education and its carefully documented Compendium of scientifically proven interventions for reducing HIV risk behaviors and transmission. The advisory council also attempted to resist political limits on HIV education, recommending to the administration that “HIV prevention materials produced or distributed by federal funding should be free of restrictions on content, subject to review only for scientific accuracy and cultural appropriateness for the targeted population. Grantees should be

given great flexibility in utilizing the least burdensome methods of conducting these reviews” (PACHA Meeting Minutes, April 1997).

At the end of the decade, the administration itself still maintained active support for comprehensive prevention education, including to teenagers, but an Institute of Medicine assessment concluded that US prevention efforts had been systematically hampered by political pressures (PACHA 2000). During most of the Clinton years, then, advocates of the comprehensive sex education approach favored by the public health leaders most knowledgeable about the requirements of effective prevention warred directly with the much more restrictive approach favored by conservatives persuaded instead by moral argument, resulting in a middle road shaped by continual political conflict.

Within the first months of the G. W. Bush administration in 2001, sex education for HIV prevention shifted dramatically once more, this time prioritizing abstinence-focused programs. Abstinence had emerged as an important concept during the 1990s: abstinence promotion became the programmatic priority for sex education in schools and family planning programs for youth, and abstinence-focused discourse was intertwined with welfare reform efforts under President Clinton (Haskins and Bevan 1997). Only during congressional budget negotiations in the final months of the Clinton administration, however, was abstinence education linked to HIV prevention (“Drugs and Sex Programs Called Effective” 1997; Kaiser Daily HIV/AIDS Report: 2/14/97, 12/2/97, 1/4/00, 1/19/00, 2/8/00, 5/17/00, 6/15/00, 12/19/00). The conservative religious groups who argued that HIV prevention education should focus on abstinence were extremely influential in the G. W. Bush administration and within Congress during these years; they soon transformed abstinence-only programs from the fringe of HIV prevention to the hallmark element of federally sponsored prevention activities. An increasing proportion of prevention funding was moved into abstinence-based programs over the next several years (Interviews with David Harvey, Harold Jaffe, and Informants 20, 27, 58; Kaiser Daily HIV/AIDS Report: 11/26/02, 12/19/02; Saltzman 2005).<sup>9</sup>

When interviewed, policy makers from both ends of the political spectrum explained that this priority on abstinence was based in moral ideology and deeply grounded in faith-based conviction, with little reference to

9. Federal funding for abstinence-only programs increased from \$80 million in 2001 to \$167 million in 2005. For a thorough summary of the shift of prevention funds to abstinence-only programs and distillation of the evidence that they do not accomplish their prevention objectives, see American Foundation for AIDS Research 2005. For more recent evidence that some such programs could be effective, see Lewin 2010.

science (Interviews with Scott Evertz, Julie Scofield, and Informants 4, 10, 23, 102, 126, 134, 157). Former members of the Bush administration remembered marshalling Christian ideology and anecdotes about abstaining from sex instead of scientific evidence, and opposing CDC programs “even if the facts were good . . . because the guy in Wichita would not be excited that his taxes were going to pay for [this kind of] prevention” (Informant 134). Opponents of abstinence-based programs remembered similar interactions: “The Governor of Texas when presented with the fact that abstinence does not work says, ‘It doesn’t matter. Abstinence works because I say it works. It worked for me and therefore it works.’ It’s nonsensical. . . . It is based on ideology and it’s based on no science or low science and it’s often based on very specific religiosity” (Informant 157).

Over mounting objections from HIV/AIDS advocacy groups that abstinence-only programs were unproven and that neglecting comprehensive sex education was dangerous for youth—and in direct opposition to recommendations by the Surgeon General and other public health experts (Gay Men’s Health Crisis 2009; Kaiser Daily HIV/AIDS Report: 6/29/01, 1/31/02, 2/5/02, 2/13/02, 2/28/02, 4/24/02, 4/26/02, 5/17/02, 3/24/03)—the new administration nonetheless clearly and repeatedly dictated that the CDC prioritize abstinence messages across the board. This message to shift the focus was delivered overtly to public health officials by administration representatives, and through oversight and management of the CDCs prevention programming and funding (Interviews with Harold Jaffe, Carl Schmid, and Informants 105, 126). Permanent “delays” in administrative approval processes also precluded publication of the CDC’s “Compendium of Effective Programs” and the Division of Adolescent Sexual Health’s “Programs that Work” guidebooks until messages counter to the abstinence priority were removed (Interviews with Informants 105, 126).

The abstinence shift was part of a general overhaul of prevention work that brought it more in line with principles that had long organized conservative thinking about HIV/AIDS. Other well-established prevention methods were now constrained as well, manifesting the renewed political power of legislators, appointees, and lobbyists representing the moralist strand of US politics organized around religious precepts condemning extramarital and homosexual sex (Morone 2003). After decades of condom promotion as a central element of HIV prevention, the Bush administration ruled that federally funded prevention programs must emphasize failure rates in order to discuss condom use, and removed condom information from government websites in order to promote abstinence (Gay Men’s



Health Crisis 2009; Kaiser Daily HIV/AIDS Report: 11/26/02, 12/19/02; Interviews with Heather Boonstra and Informants 10, 20, 28). It also lobbied (ultimately unsuccessfully) for new warning labels that would have deflected emphasis from the scientifically grounded message that condoms are the most effective available method of HIV prevention for sexually active adults and highlighted instead the fact that condoms cannot protect against all sexually transmitted diseases (Interviews with Informants 103, 105, 126; Kaiser Daily HIV/AIDS Report: 3/12/04, 3/30/04, 6/30/05). In 2005, HHS instituted a requirement that all groups receiving federal HIV/AIDS funds sign an “anti-prostitution pledge,” over the objections of health behavior experts that this position could drive an important risk group away from critical prevention services (Human Rights Watch 2005).<sup>10</sup>

Emblematic of the determination to remake HIV prevention was the push by high-ranking congressional Republicans to audit all federal HIV/AIDS programs starting in 1999 (Kaiser Daily HIV/AIDS Report: 9/10/01, 11/9/01, 11/16/01, 12/2/01, 7/31/02, 8/7/02, 8/14/02; Navarro 2004; Gay Men’s Health Crisis 2009). The most high-profile of these audits involved San Francisco’s Stop AIDS Project, whose federally funded workshops conservatives deemed “sexually provocative” and “evil” (Interview with Informant 12). After more than two years of investigation, CDC health officials concluded in 2003 that the workshops reflected appropriate public health practice grounded in scientific knowledge about HIV prevention and behavior change. Nevertheless, such audits had effects similar to those of the 1988 Helms Amendment: prodding the CDC into issuing more restrictive guidance for grant recipients, and creating an intimidating environment that pushed many HIV/AIDS educators away from the candid, comprehensive content now criticized as “skanky and gritty”

10. The centerpiece of HIV/AIDS policy under George W. Bush was not any of these domestic moves, however, but its signature PEPFAR (President’s Emergency Plan for AIDS Relief) program. Buttressed by a wealth of scientific evidence about the impact HIV-specific aid could make in developing nations, as well as strong moral arguments (of the “social gospel” variety) about the need to help those countries hardest hit by the pandemic, the Bush administration mobilized a strong cross-party coalition to provide treatment and prevention services for millions of people. The administration’s determination to organize its HIV/AIDS policy around socially conservative moral positions (of the “personal vice” variety) extended to this international arena as well. By requiring grantees to spend one-third of prevention funds on abstinence-until-marriage education, limiting condom distribution to only those at “highest risk,” and requiring grantees to explicitly state their opposition to prostitution, PEPFAR policies exported the same moral logics that were shaping domestic policy during these years. Despite the later creation of workarounds that allow PEPFAR to better address condom distribution and other prevention challenges, these policy restrictions have partially undermined PEPFAR’s ability to combat HIV/AIDS in the world’s hardest-hit nations (Evertz 2010).

(Interview with Informant 1) toward more vague, less community-specific messages (Interviews with Informants 1, 25; Kaiser Daily HIV/AIDS Report: 1/25/02, 10/1/02, 11/25/02, 2/14/03, 6/16/03; PACHA Meeting Minutes, August 2003).

While some interviewed PACHA members and Bush administration representatives framed this period as one of opening up new options for youth to protect themselves and broadening the range of prevention options valued by government (Interviews with Informants 10, 21, 31), most HIV/AIDS issue advocates (including some PACHA members) frame this period as a particularly constraining one (Interviews with Heather Boonstra, Gregg Gonsalves, and David Harvey; PACHA Meeting Minutes, June 2002, January and August 2003, March and June 2004). One advocate reflected that avoidance of HIV/AIDS issues by the Reagan and George H. W. Bush administrations constituted relatively “benign neglect” compared to this much more “aggressive attack . . . every day . . . attacking condoms, attacking needle exchange, promoting abstinence” (Interview with Gregg Gonsalves). For faith-based abstinence advocates from the political right this was a period of positive opportunity; for HIV/AIDS issue advocates—mostly from the political left—this was a period of trying to prevent the “gagging . . . of full and accurate medical information” (Interview with Informant 28) and minimize the damage to science-based programs and vulnerable populations (Interviews with Donna Crews, David Harvey, Julie Scofield, and Informants 10, 20, 24, 28, 58; PACHA Meeting Minutes, June 2002, August 2003).

With the return of the Democrats to executive power under President Obama came yet another course change, moving the emphasis of federal HIV prevention programs and expenditures back toward comprehensive sex education. During the first two years of the new administration, the president and Congress eliminated two-thirds of funding for abstinence-only programs, while increasing the overall amount spent on sex education initiatives by nearly \$190 million and channeling specific support toward evidence-based comprehensive sex education initiatives for youth (SIECUS 2012). The CDC’s materials also returned to their clear support of condoms to prevent HIV, and the agency’s efforts to summarize and disseminate scientific information about the most effective HIV prevention programs have been restored. More ambivalently, the Obama administration has showed signs of willingness to drop the requirement that federally funded organizations sign an anti-prostitution pledge, but did not actually do so—the policy was the subject of several legal challenges and was

eventually overturned by the U.S. Supreme Court in 2013 (“Two Important Rulings on AIDS” 2006; Jacobson 2009, Mazzotta 2011; Wetzstein 2013).

Federally sponsored sex education has thus been a political football, passed back and forth as the political winds change. Scientific evidence has steadily and increasingly supported the efficacy of comprehensive, candid education oriented toward changing community norms of sexual behavior, and public health experts from the Surgeon General to the CDC leadership have consistently backed this position. Conservative legislators and faith-based advocacy groups, however, have consistently and vociferously expressed arguments about the immorality of homosexual sex, extramarital sex, and prostitution, and have articulated alternate visions of HIV prevention based on these concepts. Science and morality have thus been countervailing forces in a long battle over the messages Americans should receive from their government about HIV prevention. Driven toward the comprehensive end of the sex education spectrum by HIV/AIDS activists and advocacy groups on the political left, and toward the restrictive end by religious and social conservatives on the political right, the decisive factor has usually been the ability of these motivated actors to mobilize the support of the incumbent administration. Unlike the cases of needle exchange and HIV testing, then, sex education policy has vacillated back and forth along with the political party of the president.

Sex education for those at risk of HIV is the arena of UK prevention policy in which moral counterargument has held the most sway, but even on this topic the UK has shown itself far less willing to ignore scientific evidence than the United States. In 1988, the conservative British government inserted Section 28 into the preexisting Local Government Act, making it illegal to “promote” homosexuality with government funds, in a similar fashion to the US Helms Amendment passed the same year (Costigan and Thomas 1990; Moerkerk and Aggleton 1990). Analysts have disagreed about the degree to which Section 28 created real limits on explicit education about safer sex (King 1993; Berridge 1996), but its exception for “the doing of anything for the purpose of treating or preventing the spread of disease” (Local Government Act 1988 [c.9]) paved the way for extensive government funding of candid sex education for gay men and other high-risk groups long before it was formally repealed in 2003. More recently, the British government has demonstrated a consistent commitment to comprehensive and targeted sex education in its funding of programs tailored for gay men and African migrants through careful social science research, and its open access genitourinary medical clinics

(CHAPS Partnership 1998; Padamsee 2007; NAHIP Partnership 2008).<sup>11</sup> In the context of this rarely questioned consensus about the requirements of HIV prevention, UK leaders have often found US policies on sex education intensely objectionable, on occasion even publicly criticizing their close US allies on HIV-related issues such as the G. W. Bush administration's "abstinence doctrine" and limitations on the use of condoms (Boseley 2004). While moral arguments do sometimes shape British policy in this arena, then, their influence is regularly overcome by the weight of scientific argument, and HIV prevention through sex education is thus far less volatile in the UK than in the United States.

### **Lessons on the Politically Constrained Nature of US Public Health Policy**

The debates and decisions that have shaped HIV prevention policy in the arenas of needle exchange, HIV testing, and sex education demonstrate three key lessons about the particular dynamics of public health activity in the United States. First, the influence of science is uniquely constrained in this context, such that the existence of solid evidence is not sufficient to drive national health policy choices unless other conditions are also right. With the largest and best-funded health research apparatus in the world, the United States is frequently at the global forefront of scientific research relevant to HIV/AIDS. Public health leaders and HIV/AIDS issue advocates often come to recommend new public health activity based on these findings, and sometimes thereby initiate a relatively organized process of policy revision. This trajectory characterizes the history of policy making in the arena of HIV testing, where an initial public health consensus about the value of prioritizing voluntarism and confidentiality drove a body of policy that was later strengthened as scientific findings confirmed it, and later evidence demonstrating that significant public health benefit could be gained from more routine testing in the context of HAART drove a subsequent shift in that direction. The very different case of needle exchange policy started similarly—with public health leaders recommending new activity based on scientific evidence—but then proceeded in a direction that repeatedly defied the science of HIV prevention in deference to moral

11. In the last 15 years, rare exceptions to the scientifically driven approach to HIV-related sex education have been instigated by intense publicity from the influential British media. In 2000, for instance, a local health authority was forced to cancel a weekend trip to help gay men having difficulty coming out; the trip would have been paid for with HIV prevention funds because of evidence that men with these issues often practice unsafe sex, but media attention resulted in Parliamentary-level objections (Morris 2000).

arguments. Science has had a more ambiguous impact in the arena of sex education for HIV prevention: the large body of evidence supporting comprehensive and candid approaches has often driven the development and implementation of just such programs, but has in other moments been silenced by political pressure for a much more restrictive approach.

Comparing US HIV prevention policies to their UK counterparts illustrates the relative weakness of science as a policy driver in the United States. British HIV testing procedures have generally followed in footsteps laid by US policy makers, drawing on the same science and sometimes even learning from US models. This has not been true for either needle exchange or sex education, however, where British policy makers have been more consistently guided by the scientific knowledge and public health consensus of the time. Not only have they felt compelled to institutionalize nationally funded needle exchanges and devise evidence-based, comprehensive sex education programs for populations most at risk, British leaders have also voiced strong, public disapproval of the contrary approaches favored in the United States. This difference is also reflected in the fact that experienced advocacy groups are well aware of the role of science in their national policy environments, and adjust tactics accordingly. In the UK, advocates frequently set out to generate solid scientific evidence as a key strategy that will allow them to effect changes that are politically unpopular but necessary from a public health standpoint; US advocates do work to publicize existing evidence, but often focus their energies on building the support of critical political players instead of on building the scientific case for a policy (Padamsee 2007).

The second lesson of HIV prevention history is that moral arguments can have decisive impact in the US context, even when they push policy in directions directly opposed to those scientists have demonstrated to be most effective. This dynamic has been illustrated in startling fashion by the continuous refusal of US leaders to allow federal funds to be used to provide clean needles to injecting users, despite strong evidence that such programs would reduce the spread of HIV without increasing substance abuse, and would even connect addicts with resources that could help them in broader ways as well. Behind this steadfast resistance is a set of strongly held and well-publicized beliefs about the immorality of drug abuse, and a determination not to condone such personal immorality by supporting needle exchange. Similar moral arguments have also frequently driven sex education programs toward restrictive and vague approaches that are clearly contradicted by existing knowledge about sexuality and behavior change. Emphasizing the immorality of extramarital sex and homosexual

sex, US political leaders have often insisted that HIV prevention dollars be spent promoting abstinence from these behaviors, instead of on the comprehensive sex education supported by extensive findings in the field of public health. The case of HIV testing offers a counterexample: although some politicians favored mandatory testing early on and some advocacy groups resisted routinization later in the history, neither mounted a serious moral argument as the basis for their position, so both lost out to advocates of the scientifically based policy directions supported by public health experts.

A comparative perspective on HIV prevention policy confirms that the particularly strong impact of moral discourse in the United States is the converse of the constrained influence of science on policy decisions. Whenever moral counterargument is strongly articulated in the United States—as in most debates over needle exchange, and the episodes when conservative legislators and presidents focused their attention on sex education projects—even strong scientific evidence is forced to take a backseat, while US health policy is guided primarily by moral concerns. When science and morality counterbalance one another in the UK, by contrast, scientifically supported public health opinion tends to rule the day. The passage of Section 28 and occasional later concessions to morality-based objections to interventions for gay men are exceptions to this trend. They are historically couched, however, in a broader policy trajectory that has consistently produced government-funded prevention programs built on the scientifically supported model of comprehensive, candid sex education.

Although moral argument has frequently and effectively driven US HIV policy, it is important to note that its uses in this arena represent only one subset of the ways moral argument *could* be used, and of how it *has* been used at other moments in the history of US public health. Over three decades of deliberations about HIV prevention, moral arguments have been used mostly to counter the science-based proposals of public health officials and advocates; they have rarely been used to articulate original motivations for those proposals, or to defend them against their detractors. Morone (2003) has thoroughly documented not one but two strands of morality discourse in American politics. Oriented around stigma, sin, and individual condemnation, the discourse of private vice and virtue mobilized by social conservatives represents one vision of how morality shapes our common fate, and therefore one moral basis for public policy. Also common in US history, though, has been a competing vision of public policy based in a social gospel discourse about tolerance, justice, and opposition

to oppression. This second strand of moral politics is reflected in deep normative commitments of the public health profession to values including equality and nondiscrimination. Furthermore, such arguments have been taken up by public health leaders in arenas conceptually close to HIV prevention, for instance through arguments that the “drug war” actually amounts to “incarcerating addiction” and that access to birth control can help forge strong families and lasting relationships (Morone 2003). Sometimes we can see the tracks of these arguments in the HIV arena, such as in PACHA’s protest that the Clinton administration ignored “compelling human need” in its decision not to allow federal funding for needle exchange, and public health arguments that young people should be taught about condoms to protect them from unnecessary consequences of early sexual activity even as we try to dissuade them from having early sex in the first place. Some activist groups (such as ACT-UP) and international programs (including PEPFAR) rely more explicitly on social justice arguments in favor of increased HIV prevention efforts. In most of the history of US HIV prevention policy making, however, these gestures to social gospel discourse are quiet and infrequent, in a broader context where moral arguments are the purview of social conservatives pushing vocally against scientifically motivated public health policy proposals. The situation is similar in the UK. There, moral arguments of the social gospel type may have been used somewhat more overtly by public health leaders such as the McClelland Committee very early in the epidemic’s history. Since that nation’s public consensus on HIV/AIDS policy in 1987 (Berridge 1996), however, almost all HIV prevention policy has been driven by a steadfast commitment to coping with HIV/AIDS through a science-based public health lens, and moralistic counter-arguments have been shut out of all HIV-related policy deliberations.

Why is only one strand of morality politics at play in the making of US HIV prevention policy? It may be that this reality is a long-term legacy of the earliest chapter of HIV/AIDS history, when the American religious right articulated a powerful moral argument for restrictive, punitive reactions to the new epidemic, perhaps setting a precedent that structured ongoing policy conversations around strident conflict between scientifically driven arguments articulated by public health leaders and morally based counterarguments articulated by social conservatives. It may also be that the limited uses of moral discourse in the arena of HIV/AIDS policy echo a larger trend identified by Morone: that progressives have largely abandoned the social gospel basis for politics and policy, relying in recent decades on a philosophy of classical liberalism to mount thinner arguments

oriented around individual rights instead of social goods (Morone 2003). In the context of a strong conservative moral discourse that undermines social commitments to the protection of gay men or drug users, public health leaders frequently make a tactical political choice to justify their positions on HIV prevention solely in terms of epidemiological evidence or cost-benefit analyses, strategically omitting the social justice arguments that could also be mounted.

The final lesson of US HIV prevention is that, in order to move health policy in the public health-indicated direction, it is often necessary—but not always sufficient—for vocal advocates of those policies to have the ear of the presidential administration. The importance of alignment between public health advocates and the presidency is most clearly demonstrated in the case of sex education policy. The Republican administrations of the early epidemic were very sympathetic to the concerns of social conservatives, so although the CDC moved more than once to channel federal funds into the comprehensive and candid educational programs favored by both the science of the time and HIV/AIDS activists, it was repeatedly pulled back by the administration and Congress acting in response to a powerful moral counterargument. Advocacy groups pushing for comprehensive sex education gained much more influence under President Clinton. As a result, policy frequently moved in that direction during these years, but was still limited by political pressure applied by conservative activists and legislators to move in step with moral instead of scientific arguments. Under G. W. Bush, religious conservatives once again displaced proponents of comprehensive education as those with most influence on the executive, and policy moved decisively away from the direction favored by public health leaders. In the case of needle exchange, proponents of the scientifically supported policy consistently failed to surmount the moral counterarguments, but had the most chance of doing so when they had the ear of Democratic administrations under Presidents Clinton (who was persuaded to officially support the scientific case for needle exchange, even if not the policy itself) and Obama (who lifted the ban for a brief period). Through a US lens it seems almost obvious that administrations privilege the voices of advocates whose political ideologies mirror their own, but counterexamples from the UK illustrate that it is possible for executives to take strong policy action at the behest of advocates aligned with the public health-indicated direction even if this entails moving strongly against their own ideologically based position. This happened, for instance, when Margaret Thatcher's government took a definitive position in favor of needle exchange once the scientific evidence supported it, in



spite of the conservative positions on personal responsibility and drug misuse that could have driven British policy in the same direction as its American counterpart.

Several corollaries further clarify this lesson about the positive influence of advocates for public health-indicated policies who also have the ear of the incumbent administration. First, when controversy is limited, proponents of science-based health policy may achieve their aims even without executive support. Advocates for the voluntarist approach to HIV testing favored by public health experts during the first two decades of the epidemic, for instance, pushed it forward both when they did (under Clinton) and when they didn't (under Reagan and G. H. W. Bush) have the ear of the administration, because the opposition never mounted a morally based counterargument. Second, advocates for public health-indicated policies can overcome moral counterargument with presidential support, but only if the administration is unequivocally in favor of those policies. Facing a science vs. morality battle over sex education, for instance, advocates of the comprehensive approach found an effective ally in the Clinton administration. Facing the same battle in the case of needle exchange, however, proponents tried to push their policy through the same way, but ultimately failed because the administration itself was split between the pro-needle-exchange camp led by its AIDS czar and the anti-needle-exchange camp led by its drug czar. Third, policy movement *away* from the public health-indicated direction can occur even when the sponsors of that movement do not have access to the administration, as in the case of the restrictions on sex education programs instituted by the conservative-dominated Congress of the mid-1990s, despite the Clinton administration's strong support for the comprehensive approach. Finally, access and connections to important representatives and senators in Congress influence debates in critical ways—by helping advocates get their perspectives on the table, instigate important hearings, propose legislation, and pressure the administration—but without executive support these modes of influence are not sufficient to implement policy change under controversial conditions.

Shaped by a complex interplay of scientific argument, moral counterargument, and the extent to which vocal advocacy groups can make themselves heard at the highest levels of government, the history of US HIV prevention reflects both stable and vacillating patterns by which national health policy may unfold. On some issues, policy remains relatively stable over time, guided by a singular underlying influence. This has been the case in the arena of HIV testing, where scientific conclusions about how testing procedures can support the fight against HIV have

always steered US policy, frequently buttressed by the support of well-connected advocates, and un-counteracted by morality-based objections. Needle exchange policy has been comparably stable, steered at almost every turn by a powerfully articulated moral argument that even strong scientific evidence has been entirely unable to overcome in Congress, and never definitively authorized by a presidential administration willing to act in contradiction to vociferous moral argument. On issues without such singular guiding influences, however, health policy can fluctuate profoundly. In the arena of HIV prevention this pattern is illustrated by the history of sex education, which has vacillated between policies reflecting the scientific evidence in favor of comprehensive and candid programs, and restrictive policies reflecting moral objections to homosexual and non-marital sex. Sex education policy has oscillated between these extremes because recurring battles between scientific and moral argument have been bolstered by strong advocacy groups on each side, and won in each time period by the groups most closely connected to the president.

The distinctive outcome of these three dynamics around science, morality, and advocacy involvement is that the US public health apparatus is less autonomous, and less in control of public health policy, than that of the UK comparison case. In the United States, public health leaders frequently work to advance policy proposals based on scientific research, but rarely hold the fate of these proposals in their hands. Their British counterparts often have the autonomy to drive national health policy decisions and/or the institutional power to compel politicians to act in accordance with the evidence. Advocates from outside of government do educate and push British leaders on health policy issues, but they do not drive the process. The efforts of American public health leaders, in contrast, often require the support of strong advocacy groups to move ahead, and can be thoroughly thwarted by publicly articulated moral counterargument even when those advocates are present. The British comparison thus serves to contextualize American policies within a broader range of choices a country *might* make in response to particular HIV prevention challenges. The UK contrast clarifies the dynamics of the US case by illustrating how policy choices differ in a nation where scientific arguments are more influential, and moral ones less so.

Why do we see a rockier relationship between science and health policy in the United States, and a lesser degree of autonomy in the hands of American public health leaders? Except for the relatively generous government funding of scientific research in the United States, science is organized and pursued in much the same ways in both nations. American

and British public health officials also accomplish their disease prevention work through very similar mechanisms (Padamsee 2007). The critical difference between the two countries lies in the structure of their political institutions. In the United States, legislators have the capacity to exert direct control over public health policy and activity in any areas they take an interest in. Officials at the CDC and other agencies are responsible for protecting the nation's health, but any member of Congress can initiate formal oversight procedures or initiate legislation that will change the course of national prevention initiatives. Parliamentarians in the UK, by contrast, are formally distanced from the civil service, and so do not have the same powers to directly shape the activities of the Department of Health. Incumbent governments (led by the prime minister) can shape the activities of the NHS and the Department of Health by initiating administrative or legislative policy changes that shape the mandate of civil service agencies. Individual elected officials *cannot* initiate such legislation on their own (as do their US counterparts), but can ask parliamentary questions, initiate hearings, or otherwise pressure the executive to act. This difference in political institutions has two important effects: Parliament's relatively indirect routes of influence on prevention activities protect, to some extent, both the autonomy of public health officials and the ability of British politicians to distance themselves from programs undertaken in the name of public health. Through both of these mechanisms, moral objections have less power to derail scientifically driven HIV prevention policy in the UK than in the United States.

These three lessons of HIV prevention policy are important ones for scholars, practitioners, and advocates of public health policy in the United States. For social scientists and prevention researchers, they offer a model for predicting the likely outcomes of health policy proposals stemming from our own research and that of our academic peers. Strong science can galvanize policy debate and proactive proposals, but if a moral counterargument is mounted in the public arena, we must look for investment from active, savvy advocacy groups with influential connections to the presidential administration before we can hope for our findings to translate into policy. For practitioners and advocates, these lessons name important dynamics that shape our ability to translate convictions about the best possible public health practice into functioning national programs. Challenges such as the potential for moral arguments to trump scientific ones, and the need to align advocacy efforts with sympathetic executive leaders, are already familiar to those who work in controversial areas of public health every day. Having a language in which to talk about them, though,

can facilitate the kind of strategic thinking that helps us gauge the right times and methods for advancing policy agendas that stand to create real improvements in the public health. These lessons are likely relevant beyond HIV prevention, to a range of other health arenas that incite moral debate, from the treatment of addictions to the provision of vaccines that protect young people from sexually transmitted diseases. Perhaps most importantly, the lessons learned from the history of HIV prevention policy offer a foundation for public debate about how we make health-related decisions in this country, and the potential benefits of placing more control over policies to protect the public health in the hands of the public health experts we employ to do this very job.

■ ■ ■

**Tasleem J. Padamsee** is an assistant professor of health services management and policy in the Ohio State University's College of Public Health, and faculty affiliate of the Ohio State University's James Comprehensive Cancer Center. Her research uses the theoretical and methodological tools of sociology to explore the nexus of social inequality, public policy, and health care. Her HIV/AIDS policy research centers on documenting and explaining national-level responses to the epidemic in the United States and the United Kingdom over the past thirty years. Her breast cancer prevention research includes multi-method studies of prevention decision making and health effects among women at high risk for the disease.

## References

- ACMD (Advisory Council on the Misuse of Drugs). 1988. *AIDS and Drugs Misuse, Part 1*. London: Department of Health & Social Security.
- Adam-Smith, Derek, and Fiona Goss. 1997. "Opportunity Lost: HIV/AIDS, Disability and Legislation." In *AIDS: Activism and Alliances*, edited by Peter Aggleton, Graham Hart, and Peter Davies, 25–40. London: Taylor & Francis.
- Allen, Peter L. 2000. *The Wages of Sin: Sex and Disease, Past and Present*. Chicago: University of Chicago.
- AmFAR (American Foundation for AIDS Research). 2005. "Assessing the Efficacy of Abstinence-Only Programs for HIV Prevention Among Young People." Issue Brief, April.
- Anderson, Warwick. 1991. "The New York Needle Trial: The Politics of Public Health in the Age of AIDS." *American Journal of Public Health* 81, no. 11: 1506–17.

- AVERT.org. 2012. "Needle Exchange and Harm Reduction." [www.avert.org/needle-exchange.htm](http://www.avert.org/needle-exchange.htm).
- Barr, Sarah. 2011. "Needle Exchange Programs Face New Federal Funding Ban." Kaiser Health News. Dec 21, 2011. [www.kaiserhealthnews.org/stories/2011/december/21/needle-exchange-federal-funding.aspx](http://www.kaiserhealthnews.org/stories/2011/december/21/needle-exchange-federal-funding.aspx).
- Bayer, Ronald. 2000. "Privacy and the Public Health: Conflict and Change in the AIDS Epidemic." In *The Emergence of AIDS: The Impact on Immunology, Microbiology and Public Health*, edited by Kenneth H. Mayer and H. F. Pizer, 163–78. Washington, DC: American Public Health Association.
- Bayer, Ronald, and David L. Kirp. 1992a. "Introduction: An Epidemic in Political and Policy Perspective." In *AIDS in the Industrialized Democracies: Passions, Politics, and Policies*, edited by R. Bayer and D. Kirp, 1–6. New Brunswick, NJ: Rutgers University Press.
- Bayer, Ronald, and David L. Kirp. 1992b. "The United States: At the Center of the Storm." In *AIDS in the Industrialized Democracies: Passions, Politics, and Policies*, edited by R. Bayer and D. Kirp, 7–48. New Brunswick, NJ: Rutgers University Press.
- Berke, Richard L. 1995. "Red Cross Tones Down AIDS Materials." *New York Times*, February 13.
- Berridge, Virginia. 1996. *AIDS in the UK: The Making of Policy, 1981–1994*. New York: Oxford University Press.
- Berridge, Virginia. 1998. "AIDS and British Drug Policy: A Post-War Situation?" In *Addictions and Problem Drug Use: Issues in Behaviour, Policy, and Practice*, edited by M. Bloor and F. Wood, 85–106. London: Jessica Kingsley Publishers.
- Body, The. 2004. "Home HIV Test Kits Face Fierce Fight." *HIV/AIDS Newsroom*, May 3. [www.thebody.com/content/art26288.html](http://www.thebody.com/content/art26288.html).
- Boseley, Sarah. 2004. "U.K. Policy on AIDS Leaves U.S. Isolated." *The Guardian*, July 16.
- Brandt, Allan M. 1988. "AIDS: From Social History to Social Policy." In *AIDS: The Burdens of History*, edited by E. Fee and D. M. Fox, 147–71. Berkeley: University of California Press.
- Branson, Bernard M., H. Hunter Handsfield, Margaret A. Lampe, Robert S. Janssen, Allan W. Taylor, Sheryl B. Lyss, and Jill E. Clark. 2006. "Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings." *Morbidity and Mortality Weekly Report* 55 (RR-14): 1–17.
- CDC (Centers for Disease Control and Prevention). 1987. "Public Health Service Guidelines for Counseling and Antibody Testing to Prevent HIV Infection and AIDS." *Morbidity and Mortality Weekly Report* 36: 509–15.
- CDC (Centers for Disease Control and Prevention). 1993. "Recommendations for HIV Testing Services for Inpatients and Outpatients in Acute-Care Hospital Settings." *Morbidity and Mortality Weekly Report* 42 (RR-2).
- CDC (Centers for Disease Control and Prevention). 1994. *HIV Counseling, Testing and Referral Standards and Guidelines*. Atlanta: US Department of Health and Human Services, Public Health Service.

- CDC (Centers for Disease Control and Prevention). 1995. "U.S. Public Health Service Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women." *Morbidity and Mortality Weekly Report* 44 (RR-7): 1–15.
- CDC (Centers for Disease Control and Prevention). 2001. "Revised Guidelines for HIV Counseling, Testing, and Referral." *Morbidity and Mortality Weekly Report* 44 (RR-19): 1–58.
- CDC (Centers for Disease Control and Prevention). 2003. "Advancing HIV Prevention: New Strategies for a Changing Epidemic—United States, 2003." *Morbidity and Mortality Weekly Report* 52, no. 15: 329–32.
- CDC (Centers for Disease Control and Prevention). 2008. *Reducing HIV Transmission from Mother-to-Child: An Opt-Out Approach to HIV Screening*. www.cdc.gov/hiv/topics/perinatal/resources/factsheets/pdf/opt-out.pdf.
- CHAPS (Community HIV/AIDS Prevention Strategy) Partnership. 1998. *Making it Count: A Collaborative Planning Framework to Reduce the Incidence of HIV Infection during Sex between Men*. Sigma Research. www.sigmaresearch.org.uk/downloads/report03e.pdf.
- Cohen, Cathy J. 1999. *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*. Chicago: University of Chicago Press.
- Commission of the European Communities. 2000. *Communication from the Commission on the Precautionary Principle*. Brussels. ec.europa.eu/dgs/health\_consumer/library/pub/pub07\_en.pdf.
- Connor, Edward M., Rhoda S. Sperling, Richard Gelber, Pavel Kiselev, Gwendolyn Scott, Mary Jo O'Sullivan, Russell VanDyke et al. 1994. "Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type I with Zidovudine Treatment." *New England Journal of Medicine* 331, no. 18: 1173–80.
- Costigan, Ruth, and Philip Thomas. 1990. *Promoting Homosexuality: Section 28 of the Local Government Act 1988*. Cardiff, UK: Cardiff Law School.
- DeCock, Kevin M., and Anne M. Johnson. 1998. "From Exceptionalism to Normalization: A Reappraisal of Attitudes and Practice around HIV Testing." *British Medical Journal* 316: 290–93.
- "Drugs and Sex Programs Called Effective in Fight Against AIDS." 1997. *New York Times*, February 14.
- Epstein, Steven. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.
- Ernst, Claire E. 1994. "Taking Exception: AIDS, Civil Rights, and Public Health in France and the United States, 1981–1990." PhD diss., Cornell University.
- Evertz, Scott H. 2010. *How Ideology Trumped Science: Why PEPFAR Has Failed to Meet Its Potential*. Center for American Progress, Council for Global Equality. www.americanprogress.org/wp-content/uploads/issues/2010/01/pdf/pepfar.pdf.
- Frieden, Tom R., Moupali Das-Douglas, Scott E. Kellerman, and Kelly J. Henning. 2005. "Applying Public Health Principles to the HIV Epidemic." *New England Journal of Medicine* 353, no. 22: 2397–402.
- Frontline. 2006. *The Age of AIDS*. www.pbs.org/wgbh/pages/frontline/aids/.

- Gay Men's Health Crisis. 2009. *Syringe Exchange Programs around the World: The Global Context*. [www.gmhc.org/files/editor/file/gmhc\\_intl\\_seps.pdf](http://www.gmhc.org/files/editor/file/gmhc_intl_seps.pdf).
- Guardino, Vivian, Don C. Des Jarlais, Kamyar Arasteh, Rowena Johnston, Dave Purchase, Alisa Solberg, Amy Lansky, and Dan Lentine. 2010. "Syringe Exchange Programs—United States, 2008." *Morbidity and Mortality Weekly Report* 59, no. 45: 1488–91.
- Harrington, John A. 2002. "The Instrumental Uses of Autonomy: A Review of AIDS Law and Policy in Europe." *Social Science and Medicine* 55: 1425–34.
- Haskins, Ron, and Carol Statuto Bevan. 1997. "Abstinence Education under Welfare Reform." *Children and Youth Services Review* 19, nos. 5/6: 465–84.
- Health and Human Services Press Office. 1998. "Research Shows Needle Exchange Programs Reduce HIV Infections Without Increasing Drug Use." [www.hhs.gov/news/press/1998pres/980420a.html](http://www.hhs.gov/news/press/1998pres/980420a.html).
- Heffelfinger, James D., Patrick S. Sullivan, Bernard M. Branson, Timothy D. Mastro, David W. Purcell, Sean D. Griffiths, Raul A. Romaguera, and Robert S. Janssen. 2008. "Advancing HIV Prevention Demonstration Projects: New Strategies for a Changing Epidemic." *Public Health Reports* 123 (Supplement 3): S5–S15.
- Helms, Senator Jesse. 1987. Amendment 963. *Congressional Record* 133, no. 20: 27766.
- Holtgrave, David R., and Jennifer Kates. 2007. "HIV Incidence and CDC's HIV Prevention Budget: An Exploratory Correlational Analysis." *American Journal of Preventive Medicine* 32, no. 1: 63–7.
- Horn, Tim. 2012. "Orasure In-Home HIV Test Gets Unanimous Approval Recommendation." *AIDSMEDS*, May 15. [www.aidsmeds.com/articles/hiv\\_oraquick\\_test\\_1667\\_22405.shtml?commentson=yes](http://www.aidsmeds.com/articles/hiv_oraquick_test_1667_22405.shtml?commentson=yes).
- Human Rights Watch. 2005. "U.S.: Restrictive Policies Undermine Anti-AIDS Efforts." [www.hrw.org/news/2005/05/17/us-restrictive-policies-undermine-anti-aids-efforts](http://www.hrw.org/news/2005/05/17/us-restrictive-policies-undermine-anti-aids-efforts).
- IOM (Institute of Medicine). 2005. *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White*. Washington, DC: National Academies.
- IOM (Institute of Medicine). 2011. *HIV Screening and Access to Care: Health Care System Capacity for Increased HIV Testing and Provision of Care*. Washington, DC: National Academies.
- IOM and NAS (Institute of Medicine and National Academy of Sciences). 1986. *Confronting AIDS: Directions for Public Health, Health Care, and Research*. Washington, DC: National Academies.
- Jacobson, Jodi. 2009. "Department of Justice Drops Appeal of 'Prostitution Pledge' Injunction." [www.rhrealitycheck.org/blog/2009/07/21/departement-justice-withdraws-appeal-injunction-against-prostitution-pledge](http://www.rhrealitycheck.org/blog/2009/07/21/departement-justice-withdraws-appeal-injunction-against-prostitution-pledge).
- Janssen, Robert S., David R. Holtgrave, Ronald O. Valdiserri, Melissa Shepherd, Helene D. Gayle, and Kevin M. DeCock. 2001. "The Serostatus Approach to Fighting the HIV Epidemic: Prevention Strategies for Infected Individuals." *American Journal of Public Health* 91, no. 7: 1019–24.
- Jasanoff, Sheila. 1998. *The Fifth Branch: Science Advisers as Policymakers*. Cambridge, MA: Harvard University Press.

- Kaiser Family Foundation (KFF). 1989–2009. “Kaiser Daily HIV/AIDS Report.” [www.kaisernetwork.org/dailyreports/rephiv.cfm](http://www.kaisernetwork.org/dailyreports/rephiv.cfm).
- Kaiser Family Foundation (KFF). 2009–2013. “Kaiser Health News Daily Health Report.” [www.kaiserhealthnews.org/Headlines.aspx](http://www.kaiserhealthnews.org/Headlines.aspx).
- King, Edward. 1993. *Safety in Numbers: Safer Sex and Gay Men*. New York: Routledge.
- Kolata, Gina. 1994. “Discovery that AIDS Can Be Prevented in Babies Raises Debate on Mandatory Testing.” *New York Times*, November 3.
- Koo, Douglas J., Elizabeth M. Begier, Matt H. Henn, Kent A. Sepkowitz, and Scott E. Kellerman. 2006. “HIV Counseling and Testing: Less Targeting, More Testing.” *American Journal of Public Health* 96, no. 6: 962–4.
- Koop, C. Everett. 1986. *Surgeon General’s Report on Acquired Immune Deficiency Syndrome*. Washington, DC: U.S. Public Health Service Public Affairs Office.
- Krieger, Nancy, and Rose Appleman. 1994. “The Politics of AIDS.” In *AIDS: The Politics of Survival*, edited by Nancy Krieger and Glenn Margo, 3–52. Amityville, NY: Baywood Publishing Company.
- Leary, Warren E. 1998. “Panel Urges HIV Tests for All Pregnant Women.” *New York Times*, October 15.
- Lewin, Tamar. 2010. “Quick Response to Study of Abstinence Education.” *New York Times*, February 3.
- Mathers, Bradley M., Louisa Degenhardt, Benjamin Phillips, Lucas Wiessing, Matthew Hickman, Steffanie A. Strathdee, Alex Wodak, et al. 2008. “Global Epidemiology of Injecting Drug Use and HIV among People Who Inject Drugs: A Systematic Review.” *Lancet*, 372: 1733–45.
- Mazzotta, Meredith. 2011. “An Update on the Anti-prostitution Pledge.” Science Speaks: HIV & TB News: A project of the Center for Global Health Policy. [sciencespeaksblog.org/2011/01/31/an-update-on-the-anti-prostitution-pledge/#axzz1xtBLTSCI](http://sciencespeaksblog.org/2011/01/31/an-update-on-the-anti-prostitution-pledge/#axzz1xtBLTSCI).
- McNeil, Donald G. 2012. “Rapid H.I.V. Home Test Wins Federal Approval.” *New York Times*, July 3.
- Millenson, Elliott J. 2006. “Testimony of Elliott J. Millenson.” *FDA Blood Products Advisory Committee*, March 10. [www.fda.gov/ohrms/dockets/ac/06/slides/2006-4206OPH2\\_2b.htm](http://www.fda.gov/ohrms/dockets/ac/06/slides/2006-4206OPH2_2b.htm).
- Moerkerk, Hans, and Peter Aggleton. 1990. “AIDS Prevention Strategies in Europe: A Comparison and Critical Analysis.” In *AIDS: Individual, Cultural and Policy Dimensions*, edited by Peter Aggleton, Graham Hart, and Peter Davies, 181–90. London: Falmer.
- Morone, James A. 2003. *Hellfire Nation: The Politics of Sin in American History*. New Haven, CT: Yale University Press.
- Morris, Steven. 2000. “Gay Getaway Called Off After Complaints.” *The Guardian*, November 6.
- NAHIP (National African HIV Prevention Programme) Partnership. 2008. *The Knowledge, the Will, and the Power: A Plan of Action to Meet the HIV Prevention Needs of Africans Living in England*. Sigma Research. [www.sigmaresearch.org.uk/files/report2008a.pdf](http://www.sigmaresearch.org.uk/files/report2008a.pdf).



- NASEN (North American Syringe Exchange Network). 2012. "U.S. Syringe Exchange Database." [www.nasen.org/programs/](http://www.nasen.org/programs/).
- Navarro, Mireya. 2004. "Experts in Sex Field Say Conservatives Interfere With Health and Research." *New York Times*, July 11.
- Normand, Jacques, David Vlahov, and Lincoln E. Moses, editors. 1995. *Preventing HIV Transmission: The Role of Sterile Needles and Bleach*. Washington, DC: National Research Council and Institute of Medicine.
- Obermeyer, Carla M., and Michelle Osborn. 2007. "The Utilization of Testing and Counseling for HIV: A Review of the Social and Behavioral Evidence." *American Journal of Public Health* 97: 1762–74.
- Padamsee, Tasleem J. 2007. "Infusing Health into the Welfare State: AIDS Policy in the United States and the United Kingdom." PhD diss., University of Michigan.
- PACHA (Presidential Advisory Council on HIV/AIDS). 2000. *AIDS—No Time to Spare: The Final Report to the President of the United States*. Washington, DC: Centers for Disease Control and Prevention National Prevention Information Network.
- Paltiel, A. David, Milton C. Weinstein, April D. Kimmel, George R. Seage, Elena Losina, Hong Zhang, Kenneth A. Freedberg, and Rochelle P. Walensky. 2005. "Expanded Screening for HIV in the United States—An Analysis of Cost-Effectiveness." *New England Journal of Medicine* 352: 586–95.
- Perez-Pena, Richard. 2006. "New Federal Health Policy on HIV Testing Poses Unique Local Challenge." *New York Times*, October 22.
- Poirier, Guy. 1993. "Policy Responses to the AIDS Crisis in the United States, Canada, the United Kingdom, and France." PhD diss., York University.
- Quam, Michael, and Nancy Ford. 1990. "AIDS Policies and Practices in the United States." In *Action on AIDS: National Policies in Comparative Perspective*, edited by B. A. Misztal and D. Moss, 25–50. Westport, CT: Greenwood.
- Rangel, Charles B. 1988. "Distributing Needles in New York City." *Congressional Record* Thursday, October 13, p. 30615.
- Rangel, Charles B. 1988. "Distributing Needles in New York City." *Congressional Record* Friday October 21, p. 33520.
- Ron, Aran, and David E. Rogers. 1989. "AIDS in the United States: Patient Care and Politics." *Daedalus* 118, no. 1: 41–58.
- Saltzman, Jonathan. 2005. "ACLU Sees Religious Content in Abstinence Plan." *Boston Globe*, May 17.
- Sanders, Gillian D., Ahmed M. Bayoumi, Vandana Sundaram, S. Pinar Bilir, Christopher P. Neukermans, Chara E. Rydzak, Lena R. Douglass, Laura C. Lazzeroni, Mark Holodniy, and Douglas K. Owens. 2005. "Cost-Effectiveness of Screening for HIV in the Era of Highly Active Antiretroviral Therapy." *New England Journal of Medicine* 352: 570–85.
- Scottish Home and Health Department. 1986. *HIV Infection in Scotland. Report of the Scottish Committee on HIV Infection and Drugs Misuse*. Edinburgh: Scottish Home and Health Department.
- Senate Committee on Governmental Affairs. 1986. *Coordinating the Government's Response to AIDS: Health Care and Education*. Hearings before the Committee on Governmental Affairs, United States Senate, 100th Congress, June 6.

- Shilts, Randy. 1987. *And the Band Played On: Politics, People, and the AIDS Epidemic*. New York: Penguin Books.
- SIECUS (Sexuality Information and Education Council of the United States). 2012. "A Brief History of Federal Funding for Sex Education and Related Programs." [www.siecus.org/index.cfm?fuseaction=page.viewPage&pageID=1341&nodeID=1](http://www.siecus.org/index.cfm?fuseaction=page.viewPage&pageID=1341&nodeID=1).
- Stimson, Gerry V. 1990. "Revising Policy and Practice: New Ideas about the Drugs Problem." In *AIDS and Drug Misuse: the Challenge for Policy and Practice in the 1990s*, edited by John Strang and Gerry V. Stimson, 121–31. London and New York: Routledge.
- Stine, Gerald J. 1993. "Legal Aspects of HIV/AIDS: A Review of Legislation and Court Decisions in the United States." In *Acquired Immune Deficiency Syndrome: Biological, Medical, Social, and Legal Issues*, edited by Gerald J. Stine, 393–430. Englewood Cliffs, NJ: Prentice Hall.
- Street, John, and Albert Weale. 1992. "Britain: Policy-Making in a Hermetically Sealed System." In *AIDS in the Industrialized Democracies: Passions, Politics, and Policies*, edited by Ronald Bayer and David L. Kirp, 185–220. New Brunswick, NJ: Rutgers University Press.
- "Two Important Rulings on AIDS." 2006. *New York Times*, June 2.
- Weiss, Robin, and Samuel O. Thier. 1988. "The Institute of Medicine, National Academy of Sciences: Formulating AIDS Policy." *Public Health Reports* 103, no. 3: 289–92.
- Wetzstein, Cheryl. 2013. "Supreme Court Strikes Down Obama-Backed 'Prostitution Pledge' in AIDS Funding." *Washington Times*, June 20.
- Wren, Christopher. 1998. "White House Drug and AIDS Advisers Differ on Needle Exchange." *New York Times*, March 23.
- Zibbell, Jon. 2003. *Brief History of Needle Exchange in the U.S.* [www.springfieldusers.council.org/articles/print-brief-history.html](http://www.springfieldusers.council.org/articles/print-brief-history.html).
- Zonana, Victor F. 1989. "Sullivan Shoots Down Plans to Supply Needles." *Los Angeles Times*, July 20.