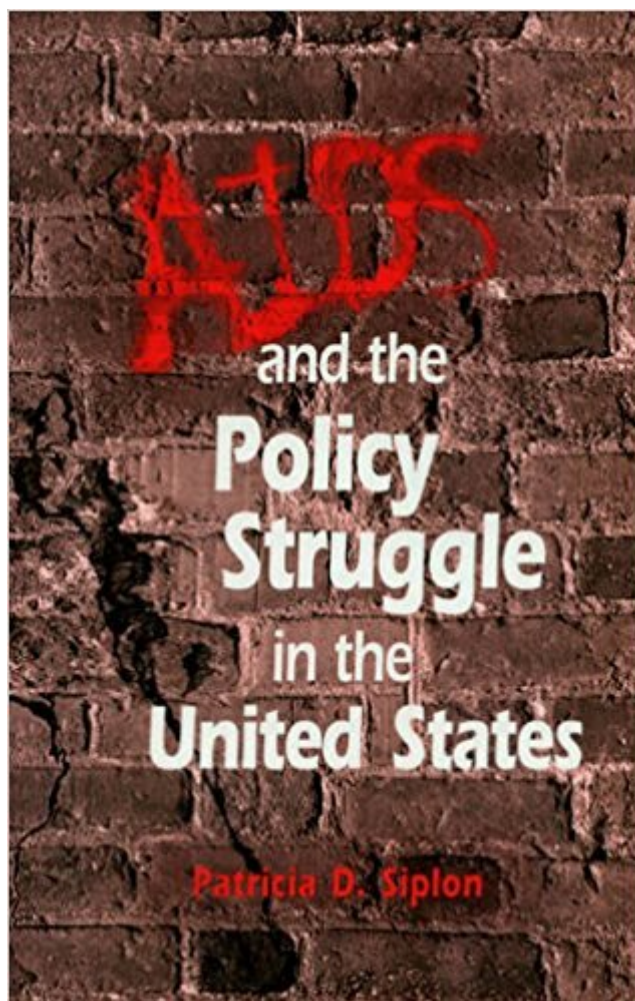


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AIDS And The Policy Struggle In The United States



Synopsis

Lucid and compellingly written, Patricia Siplon has immersed herself in the history and ongoing firestorms of how AIDS policies are influenced, fought over, and enacted in the United States. *AIDS and the Policy Struggle in the United States* is equally as engrossing and as revealing in its own way as *And the Band Played On*. With an initial chapter that clearly follows the tangled historical string from the first realizations of a medical emergency to today's overwhelming worldwide epidemical crisis, she goes on to look at how medical treatments have changed and grown; how blood policies were formed; how value-based debates raged and continue to rage over prevention; how communities developed to first respond to the crisis, and later organized to fight for health care; and finally-now that AIDS is recognized for the global crisis it is-how foreign policy is being shaped. Invaluable for activists and anyone involved in fighting for the humane treatment of people with HIV/AIDS around the world, this is also an important and insightful guide to the how and what of public policy as it is fashioned out of the clay of U.S. democratic institutions.

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Customer Reviews

"While the focus of [this book] is on detailed documentation of AIDS-specific issues, readers interested mainly in the policymaking process will also find this a valuable example of a high-stakes and controversial issue area. Siplon has filled a major gap in the political science literature with much of the passion and engagement she so clearly admires among the activists she profiles." — *Perspectives on Politics*

Patricia Siplon's book, *AIDS and the Policy Struggle in the*

United States, offers useful source material for what may be the rightful beginning of a shift toward a richer focus on AIDS as a public policy issue. . . . a compelling work about the often-problematic public-policy responses (or lack thereof) to the countless medical and social problems presented by the AIDS epidemic in the United States. . . . a terrific read."â •New Political Science

"This is an important book for political scientists, policymakers, and anyone interested in understanding the policy battles that have transformed the medical establishment, the pharmaceutical companies, and U.S. foreign policy. Patricia Siplon helps us understand the dynamics and dimensions of the U.S. government's response to the worldwide spread of HIV/AIDS. She clearly and concisely outlines the key players, their positions, and the process through which policy is formulated and implemented."â •Alan Berkman, MD, Mailman School of Public Health, Columbia University and founder of the Health Global Access Project"Dr. Siplon's analysis of governmental and corporate HIV/AIDS policy struggles demonstrates the important point that while policy decisions may appear rational, or based upon objective criteria, they are generally in fact based upon who wins the policy contest. As she states, 'policy is the product of struggles between groups.' AIDS policy has especially been a reflection of value-based conflict, and Dr. Siplon investigates the nature of the values and self-interests that underlie these conflicts. AIDS and the Policy Struggle in the United States clearly and passionately reveals the values and interests of those engaged in the policy and resource allocation struggles that directly impact on the lives of people with HIV/AIDS domestically-and internationally."â •David Hoos, MD, assistant professor of clinical epidemiology, Mailman School of Public Health, Columbia University

Below is a copy of my review of this book, which was published in the September 2003 issue of "Perspectives on Politics," a publication of the American Political Science Association.-- Raymond A. Smith, Columbia University Given the public policy significance of the AIDS epidemic, surprisingly few book-length treatments of AIDS policymaking in the U.S. have been published. Indeed, the Library of Congress lists only 35 books under its principal heading for this issue (AIDS(Disease) - Government Policy - United States), many of which are legal guides or government publications. More remarkable still is that "AIDS and the Policy Struggle in the United States" is only the third book under this heading to have been published since the 1996 introduction of the combination antiretroviral treatments that drastically cut AIDS mortality and revolutionized the policy arena. Fortunately, Patricia Siplon's lucid and engaging new book makes significant, if selective, advances in filling in the gaps in this literature. The volume opens with an overview of the

emergence of AIDS in the early 1980s, which presented the initial policy dilemma of funding research into the causes and consequences of the then-new disease syndrome. Siplon then provides individual chapters on five major policy areas, each highlighting a different dimension of the policymaking process: medical treatment (the issue of "policy definition"); blood policy ("the task of regulation"), HIV prevention ("the problem of competing values"), the Ryan White CARE Act ("the problems of distributive politics"), and foreign aid for AIDS programs ("the policy dilemma of membership"). On each of these topics, the author examines the key elements of the role of organization, the problem of "changing distributions and inflicting costs," and the role of values, the last of which has been particularly contentious in the case of AIDS. Throughout the volume, activist individuals and organizations are front and center, portrayed as actively seeking to shape policy rather than passively accept what government agencies and biomedical authorities had to offer them. The chapter on the contamination of the blood supply makes an interesting case study unto itself, but feels somewhat tangential since it involves a very distinct set of issues and interest groups, as well as policy concerns that have largely been resolved in the U.S. The remaining chapters, however, mesh together well to provide a sweeping overview of the key policy conundrums associated with the prevention and treatment of HIV. Given the breadth of this subject, Siplon must carefully select specific illustrative case studies, and those choices are for the most part successful. However, a few selections serve to limit the scope of the book, most notably the decision to focus all three of the prevention case studies on events in New York City or State. Additionally, because most of the case studies unfolded over the same period of time, readers who are new to the study of the AIDS epidemic might do well to acquaint themselves with a timeline of the epidemic (as well as, perhaps, the basics of the biology of HIV infection). Regarding AIDS treatment, Siplon provides a persuasive explanation of how a lethargic clinical trials system along with pharmaceutical company price gouging led to the launching of the protest group ACT UP, as well as a broader self-empowerment movement that has gone on to inspire numerous other patient groups. Her chapter-length recounting of the authorization (and subsequent re-authorizations) of the main federal funding mechanism for AIDS treatment, the Ryan White CARE Act, demonstrates how the changing demographics of the epidemic have influenced the policymaking process. And a concluding chapter reviews the important struggle, still very much underway, to provide foreign aid for and to promote access to affordable anti-HIV medications in the developing world. Perhaps the most compelling chapter involves the raging debate between the abstinence-only and harm-reduction approaches to HIV prevention. Whereas the chapters on treatment revolve largely around questions of money, the prevention chapter demonstrates that non-economic disagreements

can be even more hotly contested. Siplon presents three high-profile prevention controversies -- safer sex education and condom distribution in schools, needle exchange, and the testing of newborn infants - to illustrate the difficulty of making policy when two sides agree on the end of reducing HIV infections but have worldviews so different that they disagree vehemently on the means. One fascinating thread interwoven throughout the volume concerns the ever-shifting coalitions that have influenced AIDS policymaking. Time and again, Siplon teases out the logic by which the policy process creates unexpected enemies and odd allies. The battle over newborn testing pits traditional advocates of women's and children's health against AIDS groups worried about privacy rights. Well-intended proposals for needle-exchange programs in communities of color are interpreted by local leaders as an abandonment of drug treatment in their neighborhoods. Hemophiliacs originally worried about being associated with homosexuals and drug users become radicalized and form their own ACT UP-type organizations. And, most astonishingly, radical gay activists find common cause with conservative Republicans in searching out wasteful programs run by government-funded AIDS agencies. While the volume's focus is on detailed documentation of AIDS-specific issues, readers interested mainly in the policymaking process will also find this a valuable example of a high-stakes and controversial issue area. As the author herself states, a great many important issues are simply beyond the scope of this book, and we must still await a definitive account of AIDS policymaking. In the interim, however, Siplon has filled a major gap in the political science literature with much of the passion and engagement she so clearly admires among the activists she profiles.

As someone who runs a group home for boys with AIDS, I know exactly how BADLY books like this are WAY overdue. The public does NOT understand how these policies (my favorite is the Bush administration's refusal to deal with international AIDS organizations who stress condoms) are constructed and how diseases like AIDS are kept alive and kicking by policies shaped with moral not scientific agendas. This is a good book and a BEGINNING not an end. American publishers are loathe to publish such books and their indifference to AIDS is nothing less than CRIMINAL. It is a CRIME that there aren't many, many books like this. Ignorance is bliss. Being informed is difficult when institutions like publishing are committed to frivolous books and entertainment versus anything that might empower people so that they understand how their institutions work.

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