



The Left Atrium

A citizen's place is in the struggle

AIDS and the policy struggle in the United States

Patricia D. Siplon

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Understanding how policy is made in a democratic society is undeniably germane to working in contemporary politics and medicine. In this book, Patricia Siplon presents an engaging account of the development of AIDS policy in the United States over the past two decades.

Policy-making is typically depicted as a relatively sterile process in which experts gather to identify and evaluate alternative solutions to a problem, and then select the alternative with the greatest benefits and least costs. Developing and implementing policies regarding AIDS, however, has never been so straightforward, and has at every stage been a struggle, as the title of this book suggests. This is partly because AIDS has disproportionately affected members of socially and politically marginalized communities, from the AIDS 4-H Club identified in 1983 by the US Centers for Disease Control as being at increased risk (homosexual men, heroin injectors, Haitians and hemophiliacs) to people of low socioeconomic status in sub-Saharan Africa today. These people have literally had to fight to get their issues on local and national political agendas, and then to advocate for their desired policies and outcomes.

Even beyond those infected with HIV and those directly affected by AIDS, people feel passionately about AIDS policy, whether while pushing for abstinence-only education for adolescents or while advocating for access to antiretroviral medications for people in the United States and abroad. AIDS brings up fundamental and value-laden issues: Is health care a right, or a commodity? How do we allocate resources

in health care? Are people responsible (financially and morally) for the health outcomes of high-risk behaviours? How do we distribute burdens and benefits in society? When should the government intervene in or regulate the market? Who gets to make decisions? Answers to these questions set a precedent for other health and social policy issues.

In tackling this vast area, Siplon works methodically by chapter through several controversial policy areas: medical treatment, blood policy, HIV prevention, the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act, and American foreign policy regarding AIDS in developing countries. Each chapter reads much like a magazine article that you would be delighted to find and would want to photocopy and share with friends and colleagues; Siplon draws on diverse sources and crafts a coherent story from disparate activities and developments throughout the United States and the world.

Although Siplon focuses specifically on AIDS, she also illustrates ways in which the processes and outcomes of these struggles have altered the social and political fabric of the United States. Particularly noteworthy are the struggles for access to antiretroviral therapies such as AZT and to prophylactic medications such as pentamidine, and for compensation for people with hemophilia who were infected through

contaminated blood products. In these cases, AIDS patients used self-empowerment — defined as “the idea that people can and should take on action roles for themselves, rather than allowing other people to act on their behalf or make decisions for them” — to organize politically and accomplish goals, even against the resistance of established institutions and individuals in government, the pharmaceutical industry and the medical community. The results of these actions have been an arguably unprecedented level of citizen involvement in both health policy-making and in medical treatment.

It is never easy to write about a contemporary political and social issue without the luxury of perspective that time affords. Nonetheless, Siplon demonstrates remarkable insight in finding and weaving together key perspectives and issues, including those of activists, which are traditionally ignored or understated.

I would recommend *AIDS and the Policy Struggle in the United States* to anyone interested in understanding how thousands of people's actions have had and impact on our understanding of AIDS and the development of AIDS policy, or in learning who the key players in health policy-making in the United States are. We can learn from the successes and failures of AIDS policy development, where the stakes are as high as lives and quality of life, and apply these lessons to current struggles surrounding AIDS and to other social and political issues.

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Art Exposition