

## Lessons Learned from the Recent Past : A Personal Perspective on U.S. AIDS Policy

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The initial national policy response to AIDS in the United States was slow, uncoordinated and characterized by much partisan and political debate. As decisionmakers learned about a new and fatal disease spread primarily by sexual and needlesharing behaviors, cases of AIDS continued to rise and government agencies were forced to uncover and ultimately address long-standing social and health delivery problems. An indepth analysis of the complex political, sociological and systems issues underlying the early failures of the American health system to respond to the AIDS epidemic is beyond the scope of this paper. But the shortcomings of that initial response are instructive to low incidence communities and countries developing AIDS control programs.

The author presents this brief overview based on a personal perspective as a health care provider who developed AIDS education, prevention and service programs at the beginning of the epidemic and later as a policy researcher and analyst who reviewed AIDS policy response and assisted governments in managing AIDS.

The major shortcomings of initial U. S. national AIDS policy are instructive as pitfalls to avoid. Many of them have already been addressed within government agencies and institutions, some have been remedied while others are still being debated. After a brief review of these problems, the author will outline current U. S. national

AIDS initiatives and discuss some of the strategies pursued by staff of the AIDS Policy Center and other settings to educate policymakers about AIDS-- a critical undertaking which should have been completed at much earlier stages of the epidemic.

In many societies and cultures, AIDS is a disease of denial. In part, because it requires communities to deal publicly with both private and personal behaviors and stigmatized topics. But also because as beneficiaries of medical technology and science, people living in modern societies have become separated from the uncertainty and terror of much earlier epidemics. With AIDS, there was no magic bullet. No cure, except prevention. But prevention was not taken seriously by both policymakers and those at risk for infection until HIV had spread significantly. And until the cases of full blown AIDS, the "tip of the iceberg" as the Centers for Disease Control (CDC) would call them, had reached disturbing proportions.

### **Major Shortcomings of the Initial AIDS Policy Response**

Perhaps the first and most significant setback to managing AIDS in the U. S. occurred in the failure of decisionmakers to take the virus seriously. Policymakers waited too long to initiate education and prevention programs, focusing

only on the small numbers of visible AIDS cases whose apparently insignificant numbers were not perceived as a potential threat to the general population. The socially marginal status of those who were first affected by AIDS, particularly gay and bisexual men and IV drug users contributed to this initial lethargic response.

Underestimating the potential for HIV to spread, the government did not adequately fund research into the basic science of AIDS until the mid-point of the epidemic. A significant shortcoming in the research agenda was the absence of behavioral and psychosocial research when dealing with a disease that was behaviorally spread and required personal motivation to change high risk behaviors. Also absent until more recently was research into interventions with IV drug users and into the relationship between substance abuse and HIV infection. A drastic coincidence occurred between the decision of the Reagan administration to undertake significant cutbacks in the funding of drug treatment programs beginning in 1980, with the emergence of HIV -- also spread by needle-sharing behaviors. This trend would not be reversed until the latter part of the 1980's when addicts would wait months for available slots in drug treatment programs and communities would resist the introduction of new treatment programs in their neighborhoods, delaying available treatment even further.

Lack of a centralized plan for overall national management and lack of intergovernmental coordination complicated and further slowed early response efforts. While many different government agencies were responsible for various aspects of public health, these efforts were not centrally coordinated. Coupled with a reluctance on the part of the administration to deal directly with a disease that was transmitted by sexual behaviors and was prevalent initially among sexual minorities, active executive leadership was not evident until the Surgeon General and Presidential Commission on HIV highlighted many of the complex issues raised by AIDS and called for active prevention efforts. In 1988, the National AIDS and called for active prevention efforts. In 1988, the National AIDS Program

Office (NAPO) was established to share information and coordinate efforts between federal agencies responsible for health and human services. Chaired by the Assistant Secretary of Health and comprised of key representatives from each of the federal health agencies responsible for managing all aspects of the epidemic, NAPO would begin to address the challenging task of coordinating information between federal agencies. Still problematic was information-sharing between federal, state and local health agencies--many of them hard pressed by the epidemic and overburdened by patient care costs and the specter of large numbers of infected but asymptomatic residents living within their jurisdictions.

The lack of clear responsibility for educating and training several sectors of the population including health care professionals, the general public and populations at risk, led to confusion, lack of consistent information and disbelief in the assurances of federal agencies, notably the CDC, that AIDS could not be spread by casual contact.

Lack of reliable, consistent and readily available information during the early stages of the epidemic fanned the public's fear of "AIDS carriers" and contributed to panic and discrimination against people with AIDS and their families. Because the public frequently turned for information and assurances about AIDS to their family health practitioners, usually doctors and nurses, who were equally uneducated about the emerging epidemic, the problem was compounded.

Federal funds and programs to educate health care workers about the new disease were not developed until after the mid-1980's. Few model curricula were available to train the interdisciplinary providers who were needed to work with patients and their families in diverse communities. Those practitioners who learned about AIDS early on did so from working directly with patients. The lack of information sharing and centralized mechanisms to teach health care providers led to inconsistency in treatment, failure to provide accurate and appropriate treatment, discrimination against patients and on-going fear among health care workers. Early studies conducted on health care workers' attitudes, knowledge and behavior regarding

patients with AIDS showed fear, negative and judgmental attitudes about patients and their lifestyles and an unwillingness to treat them.

These fears and concerns often still persist since much provider AIDS education has dealt only with the clinical aspects of HIV and not with provider's fears, anxieties and biases, nor with the fears of their family members-- a factor that further stresses health providers working with AIDS patients.

Because health care workers, who also represent key authority figures within the society, were inadequately trained earlier in the epidemic to diagnose patients, counsel high risk patients or reduce the unnecessary fears of other patients about transmission through casual contact, an important early opportunity was lost to build public confidence, help patients change high risk behavior and calm the public's fear.

Responsibility for educating both members of the general public and those with high risk behaviors was also diffused, and large-scale national public education and prevention campaigns were not launched until the late 1980's. Much of the responsibility for educating the public was assumed by state and local health departments, by private agencies such as the Red Cross and by specially developed, privately funded community AIDS programs. While some state or local governments such as those in California and San Francisco responded early by funding public education and targeted prevention outreach efforts, others were slow to initiate education activities. As a result, many individuals did not learn about AIDS risk reduction for several years, and the numbers of cases of infected individuals continued to rise.

Targeted AIDS education programs were developed in large metropolitan areas, funded and staffed by volunteers from the gay community. Two of these programs, developed in San Francisco and New York as grass roots efforts in 1982, provided models for conducting AIDS risk reduction and education programs, counseling patients and developing innovative home care and housing programs. Adapted for use in other parts of the country (and in other countries

as well) these programs were initially funded as private endeavors. Over time, these community risk reduction programs using targeted social marketing techniques were instrumental in reducing the incidence of new cases of HIV infection in gay men to zero percent in some communities.

However, these programs were not targeted to minority communities and the incidence of HIV infection among minorities, particularly blacks and Hispanics, continued to rise. By 1983, it was already apparent that 39 percent of the cases of AIDS were among minorities but specialized federal outreach programs were not funded to these communities until 1986 and later. Today, more than 41 percent of all AIDS cases in the U. S. are among minorities and these figures are expected to rise. More than 70 percent of women with AIDS are minorities and 80 percent of all children with AIDS are minorities. Outreach programs to women were also slow to develop. By 1986, only one jurisdiction, San Francisco, funded a specialized AIDS education and outreach program to women.

A related factor contributing to the slow development and funding of initial AIDS education and prevention programs was the public and often political controversy over the level of explicitness of AIDS education materials. While this issue was debated on local and state levels, it also characterized Congressional debate. For example, the much publicized Helms Amendment was intended to restrict federal funds to only those AIDS education materials that did not discuss homosexuality or homosexual behavior.

Perhaps the most serious shortcoming inhibiting an active, direct response to the epidemic occurred with the failure to educate key policymakers about the potential ramifications of AIDS. Much time was lost as policymakers gradually learned the science of AIDS, learned about the need for prevention programs, learned the characteristics and needs of groups at higher risk for infection and learned of a range of strategies and options.

Until their learning curve peaked during the later stages

of the epidemic, much of legislation that was developed was inappropriate or ill-conceived. Opportunities for proactive prevention were lost while these issues were being debated.

This process was even more evident on the state level where most of the initial AIDS action occurred and where almost all of the AIDS related legislation was passed. Between 1983 and 1988, for example, more than 2000 AIDS related bills were introduced in all state legislatures and 346 AIDS specific laws were passed. During this time, only eight federal laws were enacted—half of them related to appropriations and funding guidelines, and only one of them allocating funds for AZT treatment to low income patients) was specifically related to AIDS.

State legislative activity peaked in 1988 when the largest number of AIDS related bills were introduced, reflecting not only the learning curve of legislators but also the result of the development of specialized AIDS legislative task forces designed to educate policymakers and to explore more thoroughly the complex social, economic and treatment issues raised by the epidemic.

As could be expected, most of the earlier legislation introduced and passed dealt with issues of testing or related to identifying who within the population was infected. As policymakers came to realize that all AIDS issues were interrelated, more comprehensive and long range topics were addressed, particularly those dealing with developing systems of care, developing specialized prevention programs, updating confidentiality safeguards to encourage at risk individuals to come forward for testing and counseling, introducing criminal penalties for the willful transmission of HIV, developing discrimination provisions and developing innovative and cost-effective options for providing treatment and care. Nevertheless, this educational process which could have been achieved directly and far more effectively, took many years to accomplish and essentially evolved as the prolonged result of constituent pressure, extensive lobbying by health advocates and patient representatives and intermittent media coverage.

## Current US National AIDS Policy

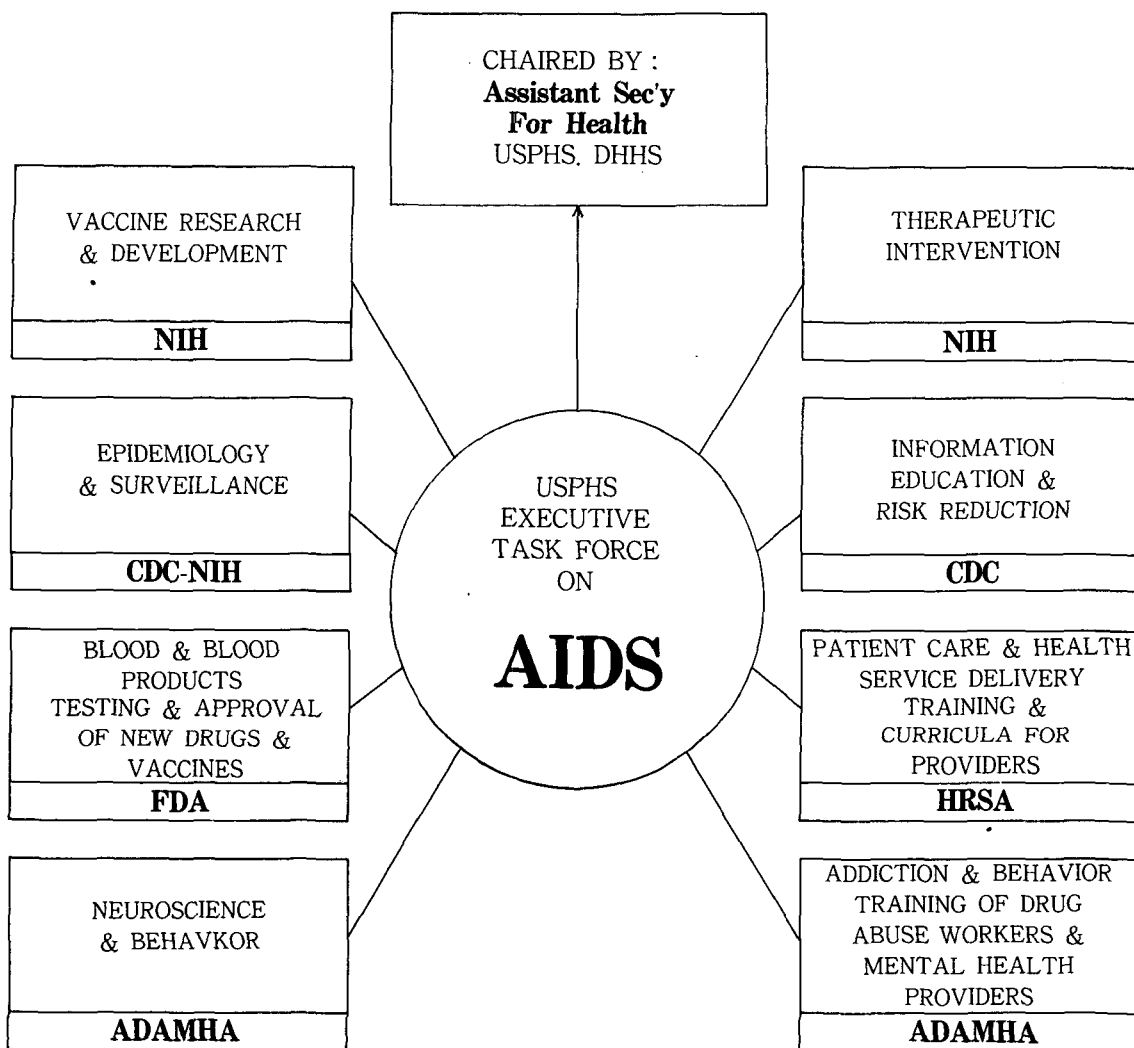
Current U. S. national AIDS policy which is coordinated through the National AIDS Program Office (NAPO) was updated based on recommendations from the government's Second AIDS Prevention and Control Conference held in June 1988. These recommendations were elicited from key health practitioners, researchers and decisionmakers working in AIDS activities throughout the country.

Six national government agencies participate in various aspects of AIDS program activities. Therapeutic intervention and vaccine research and development are responsibilities of the National Institutes of Health (NIH), currently conducting clinical trials with 62 active protocols on 25 different agents and preliminary studies on two promising vaccines. In attempting to treat the multi-problem and socially stigmatized patients infected with HIV, the NIH has expanded clinical trials into community settings in cooperation with primary care physicians serving many diverse communities. Trials were also expanded to include IV drug users, women and children. This represents the first time that the NIH has developed such an extensive community trials program and will, no doubt, affect the development of other therapeutic agents for other diseases.

The Centers for Disease Control (CDC) has responsibility for a variety of activities including national surveillance of AIDS cases and HIV infection, epidemiologic studies, the development and evaluation of new serologic and other diagnostic tests, the development and evaluation of prevention strategies and the distribution of information and educational materials.

The CDC has also implemented and expanded a national HIV seroprevalence plan for thirty metropolitan areas including other selected populations such as STD clinics, prisons and jails, college students and women of child-bearing age. In addition to assessing the level of seroprevalence for HIV, the CDC continues to monitor blood for the presence of new variants in the U. S. and is working

## COORDINATING ACTIVITIES OF NAPO



to develop more sensitive diagnostic tests for early detection.

CDC works closely with state and local health departments to support health education and risk reduction programs, as well as those for counseling and testing, partner notification and public information. Special targeted outreach efforts have been initiated to minority populations and school and college-aged youth, including the development of national and regional training centers to train school and community personnel working with youth. National education efforts have been expanded, building on the

implementation of a National AIDS Hotline System with a National AIDS Information Clearinghouse, conducting a national AIDS information mailing to every household in the country along with a national AIDS media campaign that also elicited \$18 million worth of free public service television air time.

The Food and Drug Administration (FDA) is primarily responsible for assuring the safety and effectiveness of drugs and biologics, medical devices such as condoms and gloves and the safety of the blood supply. As of

March 1989, the FDA had approved 224 Investigational New Drugs (INDs) to test 148 new AIDS related drugs, biologics, vaccines and diagnostics. Following a move initiated for cancer patients, the agency modified drug approval procedures to expedite the development and evaluation of AIDS drugs and those for other life threatening illnesses.

The Health Resources and Services Administration (HRSA) has been responsible for assisting in the development of patient care and health delivery systems and for developing training curricula for health care providers. Through a series of demonstration projects, the agency has worked to develop community models of coordinated medical care and social services focusing on case management systems to reduce cost by providing alternatives to hospitalization. New projects have been funded for women and children at risk for HIV infection with special outreach to adolescents and to areas with lower caseloads. Through thirteen regional training centers, training programs have been established to educate health professionals in the counseling, diagnosis and management of patients and families, with an emphasis on substance abuse and mental health issues at they relate to AIDS prevention and control.

The Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) supports research and training activities through three agencies. 1) The National Institute on Drug Abuse (NIDA) is conducting seroprevalence studies and studies on the needlesharing and sexual behaviors of IVDU's, in addition to providing specialized AIDS training programs for drug abuse counselors. 2) The National Institute of Mental Health (NIMH) conducts research into the neuropsychiatric aspects of AIDS with more limited studies of behavioral change and prevention. 3) The National Institute on Alcohol Abuse and Alcoholism (NIAAA) is conducting studies of alcohol use in people at risk for HIV infection.

The National Center for Health Services Research (NCHSR) is conducting specialized research for planning including surveys of patient financing costs, research

on health systems analysis and the cost effectiveness of alternative care and research on modeling the epidemic and developing disease staging and severity of illness measures.

To a great extent, federal policymakers have learned from the shortcomings of initial AIDS policies and programs. Prevention and education have become key components in managing the epidemic. Targeted education models, based on the successful efforts with urban gay men, have been adapted to reach minorities, women, IV drug users and adolescents. Training programs have been developed with model curricula for health care workers at all levels. More careful coordination of intergovernmental efforts has been initiated. And significant attention is focused on developing cost effective care.

Lower incidence cities, counties and states have learned from the mistakes of other jurisdictions and information sharing has become an important feature in managing the epidemic. While models of care and prevention strategies which have evolved are specific to the United States and to many diverse racial and ethnic groups living there, they are also adaptable for use in other countries. Much can be learned from the initial policy response to the epidemic and from innovative programming and systems that have been developed over the last eight years.

### **Implications for Low Incidence Settings**

Low incidence countries developing AIDS control programs can learn from these experiences by responding before AIDS becomes a problem. In Korea this could include :

- 1) Identifying high risk populations by undertaking an accurate assessment of their number, location, characteristics and behaviors. This would include gay and bisexual men, prostitutes, individuals with multiple sex partners, IV drug users and the sexual partners of any of these individuals.

The absence of an accurate assessment of the prevalence of these groups within the US population impeded the

formulation of more careful initial projections on the spread of HIV. The potential public health threat was thus disregarded until significant numbers of AIDS cases were reported.

2) Developing targeted education programs to these groups using successful social marketing techniques that have worked with subcultures in other countries. Small focus groups comprised of members of these populations could be formed to assist in developing special educational strategies, programs and materials that are culturally relevant and appropriate.

3) Training health care workers, particularly physicians or public health nurses to diagnose HIV spectrum disease and to counsel high risk patients (who often hide their stigmatized behaviors). High risk individuals may be more difficult to reach and educate outside of the health setting where they may not be identifiable.

4) Educating policymakers about AIDS transmission and prevention and the need for funding and developing a comprehensive AIDS control program.

Educating policymakers is a key component in developing a strong and comprehensive AIDS control program. These strategies include :

1) Make AIDS a public health and non-partisan issue. In the US significant time was lost while policymakers debated the morality of high risk behavior, were lobbied by constituent groups representing conflicting ideologies and were distracted from the essential public health aspects of managing the epidemic. Keeping them focused on public health goals and objectives will minimize political and partisan debate and assist health officials in developing appropriate AIDS programs.

2) Help them understand that a low seroprevalence rate is an important resource that can only be preserved by active prevention efforts. In most countries, policymakers waited too long--until a large number of AIDS cases were clearly evident. When AIDS affected only a small number of individuals (those who were visibly ill with more serious endstage infections) it was not perceived as a threat and policymakers did not feel that it warranted

an aggressive response. At the same time, members of the general public and those at high risk did not feel personally vulnerable enough to change their risky behavior.

3) Connect AIDS with other important health and social concerns to help policymakers understand that AIDS is connected to other issues and that making the commitment of resources to fight AIDS will be economical and useful to other prevention and health maintenance efforts. In the US, other connections were made between funding AIDS programs and stopping drug abuse, limiting teen age pregnancy, providing for the terminally and chronically ill, developing cost effective systems of care and alternatives to hospitalization, and regulating the storage, treatment and disposal of infectious waste, among other issues. In Korea, connections could be made with such issues as the need to plan cost effective care under a national health insurance plan and developing systems of outpatient and home care for patients whose family systems and needs are changing.

4) Insure that they understand the deceptiveness of a long and frequently asymptomatic incubation period during which undetected carriers have the potential to spread HIV within the population. This requires policies for the identification and management of infected individuals, notifying their sexual partners, protecting their confidentiality and protecting them from discrimination. It also requires implementation of an adequately funded long-term prevention plan.

When only a small number of AIDS cases are reported these interventions may seem excessive and costly. However, the social and financial costs of managing a large number of infected individuals far outweigh the cost of implementing an active AIDS prevention program.

## REFERENCES

- Allen, James R. Update : *AIDS and HIV Infection. Testimony before the House Energy and Commerce Committee, Subcommittee on Health and Environment, April 4, 1989.*
- Coates, Thomas J., Stall, Ron D. and Hoff Colleen C. "*Changes*

*in Sexual Behavior Among Gay and Bisexual men since the Beginning of the AIDS Epidemic."* OTA No. H3-6695, NIMH No. MH39553, NIMH/NIDA AIDS Center No. MH 42459, 1988.

Rowe, Mona and Ryan, Caitlin, *AIDS : A Public Health Challenge-State Issues, Policies and Programs, Volume I, II, III,*

*Washington, D. C. : Intergovernmental Health Policy Project, 1987.*

Ryan, Caitlin, "The Training and Support of Health Care Professionals Dealing with the Psychiatric Aspects of AIDS," In, Ostrow, David (ed.) *Managing AIDS and Other STD's.* New York : Plenum Press, 1990.