Role of State Health Agencies in Responding to AIDS

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Synopsis

State health agencies have assumed a leadership role in responding to the major public health issues raised by the AIDS epidemic. Directors of State health agencies (State health officers) have asserted their influence at the national level as well as at the State level. The Association of State and Territorial Health Officials (ASTHO), and especially ASTHO'S AIDS Committee, has served as the primary vehicle through which State health officers communicate their views to the Federal Government and vice versa.

To date, ASTHO has held four national conferences on AIDS. Each one has brought together Federal, State, and local officials, advocacy groups, and other public health experts, and each has resulted in practical recommendations to public health departments on how to implement their AIDS programs most effectively.

Although State health agencies have responded differently to the epidemic, many have adopted innovative, and sometimes unpopular, approaches. State health agencies' responses to the AIDS epidemic are governed partly by environmental factors, including the views of political leaders in the State, the strength of concerned advocacy groups, and the number of AIDS cases in the State. Despite their different approaches, State health officers have agreed that education is the most important tool in their programs to prevent human immunodeficiency virus (HIV) infections.

The rapidly changing AIDS epidemic has required State health agencies to be flexible in their approaches to controlling the epidemic. State health officers' evolving views about HIV testing and partner notification are two examples of how new information about the epidemic has affected States' HIV control programs.

AS THE AIDS EPIDEMIC HAS GROWN, it has placed demands on all facets of the public health system. While the Federal Government has assumed leadership in AIDS-related biomedical research, State health agencies have asserted their traditional leadership role in the other major areas of public health practice, most prominently in developing strategies to prevent the spread of the human immunodeficiency virus (HIV).

Several themes have typified State health agencies' response to the epidemic. In general, State health agencies have assumed leadership in addressing the many difficult public health questions surrounding AIDS, especially those questions that appear to balance the rights of individuals against the need to protect the health of the public. The varied responses of State health agencies to the epidemic underscore the fact that each agency operates in a unique environment. In addition, State health agencies and the directors of the agencies (also referred to as State health officers) have, like many others involved in the epidemic, exhibited a willingness to modify their HIV control strategies as knowledge about the epidemic has evolved.

Leadership

National level. State health officers have assumed a leading role in the public discussion about many of the key AIDS-related public health questions, both at a national level and within their respective States. The Association of State and Territorial Health Officials (ASTHO), the official organization representing directors of the State and Territorial health agencies, has functioned as the vehicle used by State health officers to assert their views at the national level. ASTHO's AIDS Committee, made up of selected State health officers and representatives from ASTHO's affiliated organizations for directors of public health laboratories, education, and epidemiology, serves as the formal

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conduit through which Federal officials communicate AIDS information to State health agencies and through which State health officers express their views to the Federal Government.

To date, ASTHO has asserted its leadership role by convening four conferences to address controversial AIDS issues. Each one has brought together Federal, State, and local officials; advocacy groups; and other public health experts; and each has resulted in practical and timely recommendations to State health agencies on how to implement their AIDS programs most effectively.

The first conference, held March 1–2, 1985, was intended to assist State and local health departments develop policies in response to the licensure of the enzyme-linked immunosorbent assay, or ELISA, test. Secretary of Health and Human Services Margaret Heckler announced the licensure of the test on March 2. At that time, because little was known about the test, ASTHO advised that the ELISA test had limited utility other than protecting the nation's blood supply. ASTHO recommended that the test not be used for generalized screening or as a precondition for employment, evidence of insurability, or admission to school or the military. ASTHO emphasized that pre- and post-test counseling were integral parts of the testing process (*1*).

ASTHO's second conference was held 5 months later in August 1985. While reiterating the principles set forth in the first conference, the report from the second conference recommended that education aimed at modifying sexual behavior be the dominant intervention strategy for most risk groups. For gay men, for example, the report's authors explicitly recommended that education be directed toward reducing the number of sexual partners and using sexual practices that avoid the exchange of body fluids (*2*).

The third conference, held in March 1986, resulted in specific recommendations to States on how to develop comprehensive HIV programs. ASTHO identified 10 elements that constituted the framework for a public health program to address HIV infection; the first two elements were considered the most important to any State plan (*3*):

- surveillance of HIV infection,
- targeted educational efforts,
- education of the public,
- community mobilization,
- provision of care,
- planning and evaluation,
- HIV antibody testing and counseling,
- contact notification,
- laboratory capabilities, and
- education and training of health professionals.

The most recent ASTHO conference, held in September 1987, focused on confidentiality and anti-discrimination principles. Following the conference, ASTHO promulgated specific recommendations to protect confidentiality and eliminate unequal treatment. ASTHO's report stated that ensuring the confidentiality of HIV-related information is critical to maintaining and promoting confidence in the public health system. The report defined confidentiality as (*4*):

> the protection from release of information without the consent of the named party which links the individual's identity to facts about HIV seropositivity, behavioral risk factors, or application for related services. Disclosure of information without the documented consent of the individual is permitted only when the disclosure:
>
> - is necessary for the individual's medical care; or
> - is required by law.

The report also said that every individual is entitled to fair treatment and protection from discrimination. Discrimination was defined as:

> the limitation of, or stated intent to limit, the rights or activities of individuals or groups because of AIDS, ARC, or HIV seropositivity, or perceived risk of same. Such limitations are not discriminatory when, based on current epidemiologic and scientific knowledge, they are required or indicated to protect others from increased risk of infection.

ASTHO's affiliated organizations have also played important roles in promoting constructive approaches to the many AIDS issues. For example, the Association of State and Territorial Public Health Laboratory Directors has held three consensus conferences on HIV testing to promote uniformity among State and other public health laboratories in HIV test performance and reporting. The Council of State and Territorial Epidemiologists has worked closely with the Centers for Disease Control to revise the case definition for surveillance of AIDS.

State level. That AIDS is an emotional issue need not be documented here. The many difficult decisions with which State health officers have been confronted during the AIDS epidemic have likely tested their leadership skills more than any issue they have faced before. As with any collection of agencies, some State health agencies have performed admirably, some less so. The few examples that follow are intended simply to illustrate the types of issues that State health agencies have confronted and to demonstrate that many have been willing to adopt sometimes innovative, and sometimes unpopular, approaches.

In November 1985, Colorado became one of the first two States to require confidential reporting of positive HIV antibody test results. As a result, the Colorado Department of Health became the focus of widespread criticism, both from within the State and nationally. Many believed that reportability increased the likelihood of breaches of confidentiality; some charged that at-risk individuals, primarily gay men, would refuse to be tested; and some believed that the risk taken by those tested would not be offset by any benefit. To date, the department of health's program appears successful. There have been no breaches of confidentiality of the State's public health records and, in calendar year 1986, the State health department tested more individuals per capita at testing sites than all but four other States.

In late 1985 the Massachusetts Office of Human Services proposed to make HIV antibody testing services available at State-funded sexually transmitted disease (STD) clinics. Gay groups in the State, as well as STD clinic personnel, had reservations about the proposal. They feared that patients would feel compelled to be tested, that patient confidentiality would be threatened, and that staff time and resources for appropriate HIV counseling would not be available. The health department worked closely with these groups in setting up the testing program, which was finally implemented in 1987. The high seroprevalence rate found at the STD clinics, about twice the rate found at alternative testing sites in the State, has proven the value of the program.

In 1986 officials of the Indiana State Board of Health worked closely with the Health and Hospital Corporation of Marion County (the county health department) to develop an ordinance to reduce the amount of unsafe sexual activity in bathhouses and book stores. The ordinance stipulates that commercial premises shall not be conducive in their structure or intended use to the type of activities that can spread communicable disease. For example, the ordinance prohibits bathhouses and book stores from using partitions that are intended to conceal and encourage sexual activity that could spread HIV. The Commissioner of the State Board of Health hopes that the ordinance will serve as a model for other Indiana counties.

In Alabama, officials of the department of public health have been vocal advocates for AIDS education in the classroom—education that includes discussion of the use of condoms. This stance runs counter to the views of many of the vocal conservative groups in the State. Despite these circumstances, the State health agency has worked closely with the State education agency to develop and implement an AIDS curriculum for students in grades 7 through 12.

The Oregon State Health Division has been recognized as a leader in actively attempting to slow the spread of HIV. The State health division initiated a statewide media campaign that included advertisements that referred to condom use. Some newspapers refused to carry the ads. In addition, many of the messages were somber in tone and focused on AIDS as a threat. The ads were intended to cause complacent persons to become concerned. Although some persons protested initially that the messages were too threatening and could potentially stimulate unwarranted fears, the concerns have not materialized.

Diverse Environments, Similar Goals

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Although State health agencies may vary in their approaches to the AIDS epidemic, their goal is

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always the same—to control the spread of HIV. State health officers have agreed that education is the most important tool in their prevention programs. Despite the wide variation in States' expenditures and case rates, every State health agency has conducted AIDS education activities. In fact, as of mid-1987, 36 States had established telephone hotlines, and 35 States maintained AIDS information clearinghouses (*5*).

Perhaps the most significant factor affecting State health agencies' AIDS programs are the laws under which each State health agency must operate, and some State legislatures have been vigorous in enacting a wide range of AIDS legislation. Some States have made HIV antibody screening mandatory for certain groups, such as prostitutes and marriage license applicants; other States have no such laws. Some States prohibit antibody testing as a precondition for obtaining insurance; others do not. Other State laws range from anti-discrimination to reporting to confidentiality to testing in prisons. To varying degrees, State HIV control programs are affected by these laws. Lewis has discussed States' AIDS legislation at length in a recent JAMA article (*6*).

Because AIDS has evolved into a highly political issue in many areas of the country, AIDS policy in individual States is often strongly influenced by the ability of the State health agency to form coalitions with concerned groups and to develop consensus positions. Most States have sought the input and involvement of a wide range of groups by establishing task forces or advisory bodies. At least 40 States have organized task forces. Some State health agencies have helped establish task forces representing specific population groups, such as the Hispanic AIDS Task Force in Michigan, to help develop HIV control programs. A number of the task forces have been legislatively mandated or created by executive order of the governor, but the State health agencies in many States have served as the catalyst for the organization of these bodies (*7*).

Among the most important groups with which State health agencies must coordinate their AIDS activities are other State agencies. Often, though, such agencies need to be persuaded to become involved in AIDS issues. Most notably, some State education agencies have been reluctant to address the need for AIDS education programs. The Michigan and Missouri Departments of Public Health are two of the State health agencies that have worked closely with collateral State agencies. Health department staff have worked with the departments of corrections to educate inmates and employees and to monitor HIV infection among inmates, with the departments of education to develop model school curriculums and distribute educational materials, with the departments of social services to monitor AIDS-related Medicaid costs and train foster care providers, and in Michigan, with the department of civil service to develop education classes for State employees.

Where to place a State's AIDS program is also usually determined by conditions unique to the State. In New Jersey, where more than half of AIDS patients are intravenous drug users, the AIDS program is integrated with the division of narcotics and drug abuse control (*7*). States with large numbers of AIDS cases have established separate organizational entities to oversee all AIDS activities in the State, for example, the AIDS Institute in New York and the Office on AIDS in California. Colorado, which traditionally has operated one of the most respected sexually transmitted disease programs in the country, has placed responsibility for AIDS programs in its STD unit.

Lastly, AIDS activities of State health agencies are sometimes dependent on the State legislature's willingness to allocate resources. In fiscal year 1986, the latest year for which complete information is available, State health agency expenditures (excluding Medicaid) for AIDS totaled nearly $65 million. Two-thirds of this money came from State appropriations. Eleven State legislatures, primarily in low incidence States, had not appropriated money for AIDS activities but relied, instead, solely on Federal funds. Other States had appro-

priated even more money than the number of reported cases in those States would suggest. For example, California, with 22.8 percent of all reported cases, accounted for 32.2 percent of all money spent by States; Georgia, with 1.7 percent of all cases, spent 5.4 percent of the States' AIDS money.

Flexibility

The AIDS epidemic has been marked by rapid changes, both in scientific and epidemiologic knowledge and in attitudes and perceptions about the disease. These changes and State health officers' relatively short terms of office—they hold their positions for an average of only about 2 years—have required State health agencies to be flexible in their approaches to controlling the epidemic. State health officers' views about testing and partner notification are two examples of how evolving knowledge about the epidemic affects States' HIV control programs.

State health officers reacted with great caution to the ELISA test when it was first introduced. Initially, they favored its use only to protect the nation's blood supply. As evidence of the test's reliability mounted, its usefulness as a control and surveillance tool became accepted. Now, of course, HIV antibody testing is a key part of each State's HIV control program.

The views of many State health officers about HIV partner notification programs have also evolved. There has been a great deal of concern among groups, especially in States with high case rates, that partner notification programs will result in breaches of confidentiality and lead ultimately to widespread discrimination. These concerns stemmed partly from misunderstandings about how partner notification works (that is, a belief that the identity of the infected person is disclosed when a contact is notified that he or she may have been exposed to the AIDS virus) and partly from uncertainty that public health departments could effectively safeguard sensitive information. Although there are many documented cases of discrimination against persons who are HIV positive, the disclosures leading to the discrimination have rarely come from public health departments (*4*). Acceptance and support of partner notification programs have grown steadily as health departments have proven that they can protect confidentiality and as the need for active public health measures to slow the growing epidemic has become evident.

Future Role of State Health Agencies

At the national level, the Association of State and Territorial Health Officials will continue to communicate the views of State health officers to Federal officials and to encourage State health officers to speak with one voice nationally on AIDS issues of critical public health importance. As AIDS issues emerge, ASTHO will continue to convene national conferences designed to educate and to foster agreement on the best approaches to the issues. For example, ASTHO, in conjunction with the National Association of County Health Officials and the U.S. Conference of Local Health Officers, will soon convene a conference on AIDS partner notification programs. The conference will, first, serve to educate—to address the concerns and questions many still have about such programs. Second, the conference will serve as an information sharing forum where public health officials can discuss specific techniques that result in successful partner notification programs.

State health agencies will continue to focus on educating people who have not modified their behavior to protect themselves from the virus and on educating the public about how the virus is and is not transmitted. For example, some States that initially focused their education efforts on selected high-risk groups are now refining their education campaigns to target groups who do not seem to have understood and acted on the AIDS messages. Some States, for example, are placing added emphasis on providing information to intravenous drug users. The New York Department of Health recently announced plans to make clean needles available to intravenous drug users who agree to enter drug treatment programs. AIDS education will be provided in the drug treatment programs.

Educating the public about HIV transmission will also continue to be a high priority for State health agencies. A September 1987 National Health Interview Survey demonstrated an extremely high national awareness (98 percent) that the AIDS virus can be transmitted by sharing needles or having sex with someone who has AIDS. However, public misconceptions about AIDS persist. Thirty-six percent of those interviewed believed it is very or somewhat likely that a person will receive the AIDS virus from exchanging saliva through kissing or from eating in a restaurant where the cook has AIDS. Many also believed that the AIDS virus can be transmitted by sharing eating utensils (47 percent), using public toilets (31 percent), and being coughed or sneezed

on by someone with AIDS (40 percent) (*8*). State health agencies can be expected to target their public education efforts on correcting these misconceptions.

Perhaps as important as educating high-risk groups and the general public is the role that State health agencies must play in educating political leaders. State health agency officials, in their frequent contacts with State political figures, must demonstrate that the epidemic demands a war against a virus, not against groups of people with unpopular lifestyles.

Finally, State health agencies must continue to address the epidemic in a manner that maintains and solidifies the nation's confidence in the public health system. Protecting the confidentiality of AIDS-related information and working to reduce inappropriate acts against infected or ill persons are important in maintaining the confidence of the public. Leaders of State health agencies are well aware that their handling of the AIDS epidemic will affect their ability to confront the future epidemics that will inevitably occur.

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