
The Institute of Medicine, National Academy of Sciences: Formulating AIDS Policy

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Synopsis

In 1985 the Institute of Medicine, National Academy of Sciences devoted its annual meeting to an exploration of acquired immunodeficiency syndrome (AIDS). The questions raised at the meeting propelled the IOM/NAS to initiate an assessment of the dimensions of the AIDS epidemic and to propose an appropriate national response.

The Committee on a National Strategy for AIDS issued its report, "Confronting AIDS: Directions for Public Health, Health Care, and Research," in October 1986. The report detailed strategies for curbing the spread of infection, and for accelerating biomedical and social science research into the causes and possible cures for AIDS.

In March 1987, the IOM/NAS established the AIDS Activities Oversight Committee to monitor and assess the nation's progress against AIDS and to coordinate the Academy's growing program of AIDS-related activities. Studies, conferences, and workshops are planned in the areas of drug and vaccine development, modeling the course of the epidemic, research in the behavioral and social sciences, equitable financing of care, pediatric AIDS, early cognitive impairment in HIV infection, IV drug abuse, and other topics.

IN 1981, THE FIRST CASES OF AIDS were recognized in the United States. By fall, 4 years later, there were more than 13,000 cases diagnosed. Against this backdrop of a growing epidemic, the Institute of Medicine devoted its 1985 annual meeting to the acquired immunodeficiency syndrome (AIDS). The detailed account of the epidemic portrayed in that day of scientific and policy presentations is related in "Mobilizing Against AIDS: The Unfinished Story of a Virus" (1). Beyond the scientific information, the day's discussions crystallized serious questions about the adequacy of the nation's response to the epidemic. Was the country mobilizing the best investigators from academia and industry? Were public health officials prepared for the probable acceleration of spread among IV drug abusers? Was there a coordinated national effort to combat the disease and its consequences? In early 1986, the presidents of the National Academy of Sciences and the Institute of Medicine, with the support of their councils, moved to initiate a special effort to assess the dimensions of the AIDS epidemic and to propose an appropriate national response.

Committee on a National Strategy for AIDS

The Committee on a National Strategy for AIDS was established, and its members asked to prepare a report within 6 months of their initial meeting. The charge to the committee was comprehensive: its study was to determine (2).

the current understanding of the virus that causes AIDS, its transmission, the natural history of infection and associated disease, the epidemiology of conditions associated with the virus, and the likely trends in these.

the nation's response to AIDS both in the public and private sector, and the current planning for research in prevention and treatment, provision of care and its financing, and public health measures.

The committee was to consider the following questions:

Are there neglected research opportunities? What are the impediments to the pursuit of these opportunities, and how can they be overcome? How can the best investigators from all sectors be

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engaged, and how can communication among them best be promoted? Is the care of AIDS patients and seropositive persons properly coordinated? What are the best approaches to the provision of care? How are the costs of care being met? Are there ways in which these costs could be met in a more rational and equitable fashion? What public health measures are desirable? What are the legal and ethical issues raised by the questions just posed; in particular, in the formulation of public health policy, how is a balance best achieved between the interests of the public and those of the individual? What are the role and the responsibilities of the United States in the international AIDS problem?

The committee established two panels, one to address issues in research and the other to address issues in health care and public health. Collectively, the panels and the steering committee included experts in molecular biology, virology, immunology, epidemiology, neurology, psychiatry, infectious diseases, general medicine, health care, public health, economics, law, and ethics, among other disciplines.

In July 1986, the steering committee held its final meetings in Woods Hole, MA, to integrate what had been gleaned from its many meetings, public hearings, commissioned papers, reviews of prepublication data, and participation in the Public Health Service's Coolfont conference and in the Second International Conference on AIDS. The committee's finding and recommendations are presented in the document "Confronting AIDS: Directions for Public Health, Health Care, and Research" (2).

The committee recommended that two major actions be undertaken to confront the epidemic of human immunodeficiency virus (HIV) and AIDS:

1. a massive media, educational, and public health campaign to curb the spread of HIV

infection through changing high-risk behavior.

2. a long-term and comprehensive program of research in the biomedical and social sciences intended to prevent or treat HIV infection and to treat the diseases that complicate it.

The committee called for increasing expenditures that would reach \$1 billion a year in newly available Federal funds for research and another billion in Federal, State, and private funds for education and public health programs by 1990.

To promote and integrate public and private sector efforts against HIV infection, the committee called for the creation of a Presidential or joint Presidential-Congressional Commission on AIDS. Such a commission would advise on needed actions and report to the Administration, the Congress, and the American people.

The committee's other major recommendations can be summarized as follows (2):

- Curbing the spread of HIV infection will entail expanding the availability of serologic testing, particularly among persons in high-risk groups, encouraging testing by keeping it voluntary and ensuring confidentiality, expanding treatment and prevention programs against IV drug use, and experimenting with making clean needles and syringes more freely available to reduce sharing of contaminated equipment.

- The care of HIV patients can be greatly improved by applying the results of health services research. In the meantime, planning and training should begin for an increased case load of patients with HIV infection, with emphasis on care in the community, keeping hospitalization at a minimum; the best ways should be found to collect demographic, health, and cost data on patients to identify cost-effective approaches to care; methods should be devised to provide appropriate and adequate funding for financing care.

- Research efforts, stated quite broadly, should enhance the knowledge needed for vaccine and drug development through basic investigations in virology, immunology, and viral protein structure; improve understanding of the natural history and pathogenesis of AIDS and trace the spread of HIV infection by means of epidemiologic and clinical research; study sexual behavior and intravenous drug use to find ways to reduce the risk of infection; encourage participation of academic scientists in research against AIDS, in part by increasing the funding for investigator-initiated research proposals; solicit the participation of

industry in collaboration with Federal and academic research programs; expand experimental animal resources, working especially to conserve chimpanzee stocks, and develop new animal models of HIV infection.

- Because AIDS and HIV infection are major and mounting health problems worldwide, the United States should be a full participant in international efforts against the epidemic, and its involvement should include both support of World Health Organization programs and bilateral efforts.

A Decision to Remain Involved

Although the primary responsibility for implementing the recommendations of "Confronting AIDS" was the Federal Government's, the IOM expected that other groups might initiate activities that would achieve the goals outlined by the committee. The committee viewed the implementation of its recommendations both in prevention and research as a matter of some urgency. With no evidence of a coordinated public-private sector national effort to combat AIDS, by March 1987 the IOM/NAS established the AIDS Activities Oversight Committee. Its charge is to monitor and assess the nation's response to the problems raised by AIDS in the areas of public health, health care, and research and to coordinate and oversee studies and activities throughout the Academy complex concerning AIDS. The committee will complete an update to "Confronting AIDS" in late spring 1988, reviewing events and progress since fall 1986.

Since the inception of the oversight committee, the President established the Presidential Commission on the Human Immunodeficiency Virus Epidemic on June 25, 1987. The IOM/NAS activities should complement the commission's efforts.

In addition, the IOM and the Academy have taken on several of the tasks implicit in their own recommendations. In some instances, the activities have produced further recommendations directed at government and policymakers; in others, the main intent is to convene relevant parties to exchange information and promote collaborative effort.

Drug and vaccine development. A conference on Promoting Drug Development Against AIDS and HIV Infection was conducted August 31 and September 1, 1987. The purpose of the meeting was to assemble scientists and other interested parties from industry, government, and academia to discuss ways to improve AIDS drug develop-

ment. The participants heard presentations describing strategies to speed drug discovery, development, testing, and licensure. Promising approaches aimed at the design of antiviral drugs capable of exploiting events in the HIV life cycle were explored. But shortcomings in communication among scientists from government, academic, and industry laboratories, and between researchers and potential recipients of treatment, was a recurring theme. Participants cited deficiencies in AIDS drug research and development, such as a failure to enlist the best investigators, a shortage of physical research facilities, a lack of suitable animal models, and difficulty in securing research reagents. "An Agenda For AIDS Drug Development," a report of the conference and the steering committee's conclusions, was issued in December 1987 (3).

A Conference on the Development of Vaccines Against HIV and AIDS was held December 14 and 15, 1987. Again, the aim of the conference was both to review the most recent scientific developments and to evaluate the coordination and design of vaccine development activities. Because no vaccine has proven effective in altering the course of infection in chimpanzees, fundamental research in vaccine design and testing remains a major need. Conferees underscored the dilemma between the well-established pattern of demonstrating protective efficacy of a vaccine in animals before tests in humans and the urgency of the demand for a safe and effective prophylactic for AIDS. Additional animal models remain a critical unmet need.

A discussion following the vaccine conference identified issues of liability and insurance which may impede the testing and marketing of an HIV vaccine.

On the basis of these two conferences, the IOM/NAS intends to establish a roundtable on the development of drugs and vaccines against AIDS; its goal will be to bring together interested parties from the private and public sectors to speed research, testing, and availability of therapy for HIV infection.

Modeling the course of the epidemic. Mathematical models of several types have been used to project the incidence and prevalence rates of HIV infection and AIDS over time, to predict AIDS-specific mortality rates, and to assess the potential impact of educational interventions on these rates. The IOM convened a workshop on October 15-17, 1987, to review the state of the art of modeling epidemics, to evaluate the proper application of

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different classes of models, and to develop recommendations to improve the effectiveness of models. A major point of agreement among the participants was the extent to which models rely on a constrained set of data elements of varying validities and reliabilities; the limited data base is so heavily used by the different modeling groups that consensus about the validity of the data appears to be stronger than it actually is. A second workshop, to identify common data needs of modelers and to propose mechanisms for gathering data, is planned. The IOM and the NAS, through its operating arm of the National Research Council (NRC), plan to play a continuing role in the refinement and use of mathematical models to predict the demographic impact of AIDS in the United States and worldwide.

The behavioral and social sciences. The Committee on AIDS Research and the Behavioral and Social Sciences, established within the NRC Commission on Behavioral and Social Sciences and Education, is preparing a report that will review what is currently known about behavior that transmits infection in the United States. The committee's work, scheduled to be fully completed in 3 years, will include an analysis of public education efforts, identification of data needs, and an attempt to offer leadership in setting research agendas for the social and behavioral research communities.

Other studies and activities. Other studies are in various stages of development. Among them are investigations into the equitable financing of AIDS care; the treatment of IV drug abuse as it relates to AIDS prevention; evidence of early cognitive impairment in HIV infected individuals, and an examination of the process for translating such evolving and incomplete information into policy; responding to stress in AIDS caregivers; the pre-

vention of pediatric AIDS and the provision and financing of care for pediatric AIDS patients; and the coordination of international efforts to combat AIDS.

Conclusion

The Institute of Medicine and National Academy of Sciences have taken an active role in formulating public policy for AIDS since 1985. As the epidemic continues, increasingly complex issues emerge; the IOM/NAS will continue to provide expert data-based analysis to address them.

References.....

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