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Report of

THE PRESIDENTIAL COMMISSION

on the

HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

Submitted to
The President of the United States

June 24, 1988

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CHAPTER FIVE: THE PUBLIC HEALTH SYSTEM

The HIV epidemic has presented a tremendous challenge to this nation's public health and education systems. The preventive response to the epidemic must be multidisciplinary, involving the public health community, the traditional education community, private and public health care providers, and substantial involvement of private, voluntary initiatives. The response must also be flexible and creative, not bound to a single approach.

The public health system, a system which has been fighting disease and promoting the general health of our nation's population for more than a century, has the primary responsibility to provide leadership in the design and implementation of strategies intended to halt the spread of HIV. The public health system cannot, however, lead in a vacuum. It must actively seek participation and cooperation from individuals who have in the past been considered outside that system. Prevention and education strategies that are not coordinated and that do not include input from all sectors of society will not succeed.

The basic legal framework of the public health system is the public health laws of the states and territories which give authority for the protection, preservation, and promotion of the health of the population. The federal government, through the Public Health Service (PHS), has the responsibility for protecting the nation as a whole and for coordinating among and providing technical assistance to the state and local agencies. Local public health agencies (city and county) act under local ordinance or a delegation of state law to serve a more limited geographic area. National efforts, such as the universal reporting of syphilis and rabies, are carried out by the voluntary coordination of the states and territories working through local agencies and in collaboration with the key federal agency, the Centers for Disease Control (CDC).

Section I. The Federal Role

While many branches of PHS contribute to prevention, CDC is the lead agency in this endeavor. The Epidemic Intelligence Service was created within CDC in the 1950s to provide a highly trained and mobile work force which could be quickly deployed to investigate a public health emergency. CDC is charged with: preventing and controlling infectious and chronic diseases; preventing disease, disability, and death associated with the environment and the workplace; and reducing health risks through education and information. All of these are done in partnership with state and local health agencies.

CDC began its AIDS efforts in the spring of 1981 by conducting epidemiologic and laboratory investigations to determine the cause and document the epidemiologic trends. The use of a nationwide communications network alerted all states to the epidemic in 1981 and encouraged state and local interest in the new condition. Some members of the Epidemic Intelligence Service as well as other CDC employees were diverted from their regular duties into a variety of special projects designed to better understand this new disease. The following year, CDC provided New York City with federal funds for its surveillance program. In 1983, additional funds were provided by CDC to states and cities that had the largest number of AIDS cases. 1983 also marked the year that CDC, in conjunction with state epidemiologists, determined that AIDS should become a reportable condition, and appropriate instructions were issued by every state. In 1985, CDC

began allocating funds to state and local public health departments for AIDS information and education initiatives. Counseling and testing programs became part of CDC's funding agenda in 1986. No funds for overall program management were included. CDC's education plan further expanded in 1987 with the establishment of the National Aids Information and Education Program Office, whose purpose is to provide mechanisms that will educate and inform the public. CDC's planned HIV activities for 1988 include an AIDS information mailer that was sent to every American household in May and June, the establishment of a clearinghouse that will serve as a reference center where the public may obtain information concerning the HIV epidemic, and further expansion of surveillance activities.

A critical role of CDC is its leadership for state policy design and its collaboration with state public health agencies in surveillance. Although CDC's definition of AIDS originally defined the problem well as it was early understood and assisted scientific and public understanding as well as originally possible, CDC has lagged behind scientific understanding by not moving to an HIV infection-based data collection system when the antibody test was developed in 1985 to detect infection in asymptomatic persons. It is critical that CDC work with the states to collect HIV infection data and end its focus on symptomatic disease.

CDC's HIV efforts have illustrated the agency's strengths and weaknesses that must be discussed in defining CDC's role in combating the HIV epidemic. The areas to be examined include: CDC's budget; its structural organization; its personnel; its location; and its AIDS education and information programs.

Section II. The CDC Budget

Since 1981, CDC's AIDS budget has significantly increased from $200,000 to approximately $305 million in FY 1988. Today, AIDS represents 40 percent of the CDC budget. During this same time period, very few CDC programs have realized as much growth as its AIDS activities.

Obstacles to Progress

In order for CDC to expand its prevention efforts, the following obstacles must be overcome:

- Prevention programs are budgeted via annual appropriations, while federal illness treatment programs are entitlements that allow continued access to funds. This limits the ability to plan programs over long periods of time, though most prevention efforts must be multi-year and will not have "pay-off" in reduced mortality or morbidity during the first 12 to 24 months of program activity. For example, there are no entitlements for immunization for all children in the United States. There are just year-to-year dollars eroded by inflation. On the other hand, annual appropriations maintain the opportunity for oversight and accountability.

- There is a lack of sufficient funds for many CDC programs. CDC's overall budget has received only slight increases in recent years. For the most part, these increases occurred within the HIV budget, while the other CDC programs have basically remained level funded or have been tapped to augment HIV needs. A key example that illustrates CDC's budgeting constraints is its funding allocation for sexually transmitted diseases (STDs) other than HIV. For FY 1988, the federal government has allocated $65 million for STDs (this does not include funding for HIV). For FY 1989, the President's budget request includes less than a $300,000 increase for the STD program. While the budget request accounts for little more than inflation in funding STD activities, a resurgence in STDs is apparent in many parts of the nation. From 1986 to 1987, infectious syphilis cases rose 30 percent. The HIV epidemic has had an adverse impact on the availability of senior scientists and public health advisers for STD investigation and control.

RECOMMENDATIONS

5–1 The Department of Health and Human Services should propose and Congress should support mechanisms to sustain longer term commitments to prevention programming than are now the case. Such mechanisms must include annual accountability for programs and regular evaluation of the effects of prevention services.

5–2 Without reducing funds for other prevention activities under the Centers for Disease Control's (CDC) jurisdiction, appropriations to CDC should include not only funds for direct activities and pass-through allocations to state and local governments, but also funds for the management and evaluation of HIV-related activities.

5–3 Sexually transmitted diseases (STDs) are believed to be a significant co-factor of HIV infection. Recognizing this relation-

ship, the Centers for Disease Control should significantly increase its FY 1989 funding for STD programs.

Section III. CDC Management

HIV prevention activities in CDC are distributed through eight entities. These are: the Office of the Deputy Director for AIDS, which supervises all of CDC's HIV activities; the National AIDS Information and Education Program, which disseminates information to the public; the Center for Infectious Diseases, which is in charge of surveillance, epidemiology, and laboratory science; the Center for Prevention Services, which handles target groups, health education, and risk reduction; the Center for Health Promotion and Education, which administers the school health education program; the National Institute for Occupational Safety and Health, which examines HIV in the workplace; the Training and Laboratory Program Office, which handles laboratory evaluation and training; and the National Center for Health Statistics, which conducts health interview surveys. In order for CDC's HIV programs to succeed, it is crucial that the eight offices involved with HIV programs interact frequently and coordinate their efforts and that the agency shift focus to include the full spectrum of HIV disease.

Obstacles to Progress

- The "matrix management" model, which has most HIV personnel reporting their activities in a line to both a major subunit of CDC and to the Deputy Director for AIDS, is confusing. Persons seeking information and assistance from CDC may not find it quickly. Activities in one area may not be coordinated with related activities in another center.

- Continued use of the term "AIDS" rather than "HIV" in program titles and written materials contributes to the national confusion regarding this disease.

- The continued CDC focus on AIDS case reporting is blocking efforts to track the epidemic and to plan, target, and implement prevention strategies and is misleading the public as to the urgency of the problem.

RECOMMENDATIONS

5–4 The Centers for Disease Control (CDC) should design and immediately implement an internal plan for coordinating all of their HIV-related efforts. This task should be completed by September 30, 1988. Such a plan should specifically state the responsibilities of all CDC units that are involved in HIV programs. It should also outline the coordination and communication processes between all participating CDC entities.

5–5 The Centers for Disease Control (CDC) should establish by August 1, 1988, a clear and comprehensive mission statement for the Office of the Deputy Director for AIDS. This statement should include the specific duties for that office as well as how that office will relate to all divisions of CDC.

5–6 The Centers for Disease Control should immediately emphasize its focus on the HIV disease, collecting data beginning at infection.

Section IV. National AIDS Information and Education Program

The National AIDS Information and Education Program (NAIEP) was established in April 1987. Its purpose is to provide a focus for CDC's public information and education endeavors related to the HIV epidemic. NAIEP is intended to serve as a link to national and community-based organizations that are essential in providing comprehensive HIV information and education.

For its first year of operation, NAIEP operated on a budget of $23.6 million. Its budget for 1988 is slightly over $41 million. NAIEP's activities include:

- direction of the National AIDS Information Campaign. The information campaign is a media-based public information effort intended to relay to the public facts about HIV. The contract for the campaign was awarded to a large public relations firm. Some of the campaign's activities include public service announcements and a national mailing to every American household regarding HIV. The campaign's goal is to positively influence the public's knowledge and attitudes concerning HIV. The contract is presently funded at $7.9 million with several outstanding change orders. The estimated cost of these modifications is $1.4 million.
- direction of the National AIDS Clearinghouse. The clearinghouse is also operated through a contract with a private organization. It is intended to serve as a resource center for materials discussing AIDS and HIV infection. For FY 1988, the clearinghouse is funded at $2.2 million.

- direction of the National AIDS Hotline. The hotline is also operated through a contract. Since the awarding of the contract in 1986, the hotline has been funded at $8.5 million.
- funding of minority outreach programs. Currently NAIEP administers the Minority Outreach Program which, through grants and contracts, is intended to assist national and regional organizations in developing minority initiatives that will target HIV information to minority populations. Funding for minority initiatives for FY 1988 is $19.5 million.

The NAIEP office must not only serve as a facilitator, but also as a coordinator for information and education programs. After one year of existence, it appears that there are several obstacles blocking NAIEP's path to functioning effectively.

Obstacles to Progress

- After more than one year of existence, this office has yet to determine its goals. A cohesive plan of action and sense of mission is lacking. NAIEP has contracted with a private organization for the purpose of developing its own goals and objectives.

- There is an absence of communication among the various CDC entities regarding CDC's HIV activities and programs. This has resulted in a lack of coordination regarding a national HIV prevention and education plan.

- NAIEP has contracted out the majority of its significant activities. Because of the limited number of full-time equivalent staff positions (FTEs) and the lack of direction and coordination within NAIEP, there has been limited and sometimes inconsistent guidance from CDC regarding contract implementation and oversight.

RECOMMENDATIONS

5-7 The Centers for Disease Control should devise its own program goals and objectives, and should not enter into contracts with outside consultants for this purpose.

5-8 The Centers for Disease Control should move the National AIDS Information and Education Program (NAIEP) to the Center for Prevention Services by September 30, 1988. This will avoid any duplication of activities that is presently occurring between NAIEP and the Center for Prevention Services.

Section V. CDC Personnel and Infrastructure

From FY 1981 through FY 1988, a total of 165 new personnel positions (FTEs) were added to CDC for HIV activities. For FY 1988, CDC has 416 FTEs assigned to HIV initiatives. Of this total, 251 FTEs have been diverted from other CDC efforts. Thus, the HIV epidemic has placed a severe strain on CDC personnel and functions. Additional personnel are urgently needed at CDC to expand both CDC's HIV programs and other CDC activities. In order to accommodate additional personnel, additional facilities will be necessary.

Obstacles to Progress

- Past FTE ceiling restrictions on hiring middle to upper grade levels of personnel have resulted in a decreasing number of these workers in the federal government. It has become common practice within the federal government that positions vacated by reassignment, promotion, or retirement are eliminated by attrition.

- The federal government's salaries and benefits packages often hamper the recruitment of quality personnel by CDC. Many qualified scientists and physicians who are interested in working for CDC will not do so because salaries are significantly lower in the public sector than in the private sector.

- The diversion of personnel from other programs within CDC to staff HIV programs has resulted in delays in other important public health programs. Specific health initiatives that have been delayed or not fully implemented because of personnel diversions include: expansion of efforts to control sexually transmitted diseases -- especially revising and updating training courses for STD control; development of programs to reduce and prevent injuries that result in chronic disabilities; building CDC's behavioral science capacity, an area essential to understanding which are the most effective prevention programs for injuries and disabilities and the best control programs for infectious and chronic diseases; implementing an intensive review of the prevalence of hepatitis A in the United States; and implementation of programs to prevent or reduce smoking during pregnancy.

- CDC is confined to a small and outmoded facility. The Office of Management and Budget (OMB) has thwarted recent attempts by CDC to expand and modernize this facility. Being housed in an antiquated facility has severely hampered CDC's ability to respond effectively to the HIV epidemic. In March 1988, OMB sent a memorandum to the President describing CDC's request for the construction of additional facilities as "wasteful." In contrast, in a November 1987 letter to Dr. James Mason, Director of CDC, from the General Services Administration (GSA), the GSA stated, "It is our commitment to support the Centers for Disease Control in your ef-

forts to upgrade and replace your aging physical plant at Chamblee, Georgia."

RECOMMENDATIONS

5-9 The Centers for Disease Control (CDC) must be adequately staffed at all times in order to successfully meet its public health mission, including HIV programming. The Commission's analysis of current and proposed HIV programs at CDC indicates that a total of 523 full-time equivalents will be required to be permanently assigned to HIV activities for FY 1989. CDC should be allowed to hire new staff in sufficient numbers to replace those personnel who have been diverted from other programs, *and* staff HIV-related programs with a full compliment of 523 full-time equivalents for FY 1989.

5-10 Congress, in conjunction with the Office of Personnel Management, should analyze the recruitment of personnel to the Centers for Disease Control (CDC). Federal salaries and benefits should be assessed. Following such an analysis, Congress should make every effort to enact legislation that will attract first-rate personnel to CDC.

5-11 The Office of Management and Budget (OMB) should follow both the General Services Administration and congressional mandates regarding the construction of facilities at the Centers for Disease Control. OMB should not undermine congressional intent.

Section VI. The Role of the State and Local Departments of Public Health

The state and local components of the public health system consist of state or territorial health departments, thousands of county and city health departments, as well as private, voluntary organizations such as community-based service organizations or community and migrant health centers. The structure and operating procedures for each of these organizations vary from locality to locality depending on a number of variables, including state or local law, the size of population served, and available financial resources. In some areas, city and county health departments operate only under state law, but receive local as well as state and federal funds. Other city and county health departments follow mandates established by their local governments that augment state law. In areas where local health departments are in place, the state health department often guides policy and functions in the important role of a coordinating body and the supplier of technical assistance. Many smaller cities and counties have no local health departments and receive public health services only from the state agency.

State and local public health agencies have several general responsibilities for any condition that affects the health of the general population. First, components of the local public health system collect and interpret surveillance data about a specific condition through the implementation of epidemiological studies and reporting of selected conditions by physicians, laboratories, and other elements of the health care system. Second, using the information gathered from such studies, local public health agencies then plan and implement programs to interrupt the spread of disease. Such programs may include public education campaigns, identification of infected people through the use of testing and partner notification mechanisms, or any other intervention designed to change behaviors in people who are at risk of becoming infected with the disease. Third, local public health agencies have the responsibility to provide selected treatment services for those members of society who cannot pay or who lack access to the health care system. Fourth, as a last resort, local public health agencies can use restrictive measures such as isolation to control the spread of disease. Fifth, local public health agencies evaluate the effectiveness of their efforts in controlling the spread of disease, identifying those strategies that have been successful and those that have failed. The sixth and final general responsibility of local public health agencies is to support appropriate community systems which contribute to the above. All of these are applicable to the HIV epidemic; however, there are obstacles to their full implementation.

Obstacles to Progress

- Funding for most HIV education and prevention programs occurs through grants. Due to the bureaucracy surrounding grant applications, valuable staff hours are continually used for filling out grant applications and not for direct delivery of prevention services.

- There is a lack of effective evaluation models and tools that can be applied to HIV prevention and

CHAPTER SIX: PREVENTION

Although the HIV epidemic has presented the public health system with a new set of challenges, the prevention of disease has been the primary mission of that system since its inception. Prevention refers to any action that interrupts or halts the progressive path of a disease. Effective preventive interventions which can be applied to the HIV epidemic include the implementation of widespread testing and counseling, partner notification, the pre-donation screening of potential blood and semen donors, the testing of donated blood and organs, restrictive measures, and the implementation of general and targeted education programs. Education is addressed in its own chapter. This chapter will address the other preventive measures mentioned above.

Section I. Testing and Counseling

The HIV antibody test is used for several reasons. First, it can determine an early clinical diagnosis of HIV infection which should immediately establish a strong link between an infected individual and a primary health care provider. Second, it is used to screen donated blood, organs, breast milk, and semen to protect the eventual recipient. Third, test results are used to establish incidence and prevalence data, critical to monitoring the epidemic. Fourth, test results can be used to initiate a process whereby partners are warned of their exposure to the virus. Finally, testing and counseling are a vital component in encouraging positive behavior change in an individual. The first four uses of the HIV antibody test are discussed elsewhere in the report. Here, we will focus on testing and counseling programs used as a vital component of an overall prevention strategy to promote behavior change in order to stem the spread of HIV infection.

Only a limited number of individuals potentially infected with HIV have been counseled and tested, and only a limited percentage (approximately five percent) of those infected with HIV have laboratory confirmation of their infection due to a lack of information, fears of testing, or limited access to voluntary testing and counseling services.

Testing provides an opportunity for effective education and counseling and, for some, the initiation of behavior modification. When a person has volunteered to be tested, or when his or her physician has determined with the individual's consent that an HIV antibody test is appropriate, the tested person's interest is elevated; in short, he or she is more likely at this point to pay attention than in merely receiving impersonal educational messages. The type and intensity of education and counseling linked to testing ought to be guided by two factors -- the test result and the reason the person offers for being tested. If the test result is negative, a simple brochure accompanying the result could, in some cases, suffice.

If a person expresses concern that his or her own behavior has led to the test or appears agitated at the time the blood is drawn, person-to-person counseling is appropriate both before and after the administration of the test. Particularly, counseling should be available for these persons between the time the test is administered and the result is known. The person who has participated in high-risk behavior but has a negative test result should receive counseling in an effort to ensure that he or she remains uninfected.

If the test result is confirmed positive, intensive counseling at the time the result is given is needed. Because of the significance of that result and the natural tendency for the infected

person to block out much of the information given at the initial session while concentrating on the result itself, it is imperative that the initial counseling session include the presentation in writing of the implications of the test result and of the opportunity for further testing and for further counseling, which may be by referral. An effort should be made at the initial counseling session to link the infected individual with a primary care provider if that link does not already exist. Consideration should be given to providing take-home materials, such as brochures or audiotapes, so that the infected person can review the information at home if he or she so chooses.

Counseling of infected persons should also include the means to and the responsibility to avoid transmitting the virus to others, the responsibility and benefits of telling one's sexual or drug-using contacts about the test result, and the availability of public health services to inform those partners should the person be unable or unwilling to do so.

Many have suggested that testing should not be done in any circumstance without interpersonal counseling. This appears to be current public health policy, except in blood donating settings. While still using the testing process to promote education, however, it would be more prudent to differentiate the handling of those whose need for counseling is apparent from those for whom a simple brochure will suffice. Additionally, pre-test counseling can burden those who decide to seek an HIV test if done inappropriately. In some jurisdictions, pre-test counseling includes commentary which might discourage the person who has considered long and hard whether to seek the test. Pre-test counseling should support the decision for the test, should provide the person with basic information about the medical implications of the test, including the fact that diagnosis can lead to treatment and care, and should attempt to elicit the reasons the person is seeking to be tested without passing judgment on the decision.

Testing and pre- and post-test counseling for HIV should be available in a timely fashion for any individual who wishes these services. An adequate number of testing facilities must be made available for those individuals who have no personal physician or who will not seek testing services from their physicians so that any individual can determine whether he or she has been infected and can receive counseling, if needed, about healthy behavior.

Obstacles to Progress

- The perception that confidentiality may be breached is keeping people who believe that they may have been exposed to the virus from seeking testing and counseling services.
- The Commission heard from numerous witnesses who had been the target of discrimination as a result of a positive HIV antibody test. Some persons who fear such discrimination because of a positive test result or even admission that such a test is desired are choosing not to be tested.
- Access to voluntary testing is limited; long waiting periods in densely populated areas and lack of testing facilities in rural areas are impeding the ability of individuals to determine whether or not they are infected.
- State and local departments of health do not have adequate funding available to provide testing and counseling services on the scale that is needed for those who either cannot or will not get those services in the private sector.
- Many private physicians do not regularly offer HIV antibody tests to their patients, resulting in increased demands on public testing and counseling centers.
- Demand for service exceeds capacity at existing testing sites, both anonymous and confidential, in many areas. This results in unreasonably long waiting periods to receive both the administration of a test, as well as the communication of the result together with its appropriate counseling.

RECOMMENDATIONS

6–1 States should adopt statutes that ensure confidentiality in testing and in reporting to public health authorities.

6–2 People who fall into any of the following categories should seek testing and counseling services from their physician or public health agency, regardless of the presence or absence of symptoms:

- recipients of blood, blood products, donated semen, or organs since 1977.
- intravenous drug abusers.
- men who have engaged in sexual activities with other men.
- persons who have engaged in sexual activities with more than one partner since 1977.
- any person who believes his or her sexual partner, either current or past, is any of the above.

6–3 Voluntary testing for HIV infection on a nationwide basis should be widely encouraged by government at all levels, and physicians and other health care professionals should promote voluntary testing for their potentially exposed patients. To facilitate the performance of such tests, a variety of facilities such as mobile vans should be made widely available by funding through public health agencies and by the private sector.

6–4 Each state, through the local public health system, should increase the number and availability of anonymous and/or confidential testing and counseling sites.

6–5 State departments of health should make new funds available that will ensure that HIV testing and counseling services are a part of the services offered by sexually transmitted disease clinics, family planning centers, drug treatment clinics, and community health centers.

6–6 Private physicians should regularly offer their patients the opportunity for an HIV antibody test.

6–7 State and local departments of health should aggressively advocate the use of HIV testing and counseling services through public health education campaigns. These should highlight the assurance of confidentiality in order to induce more individuals to use the public health system. Special efforts should be focused on those geographic areas or members of groups in which there is evidence of high seroprevalence.

6–8 An incentive grant program should be created to support voluntary testing in counties or other well-defined geographic areas where the incidence of HIV infection rises above a designated level. These funds should be made available by the Centers for Disease Control on an expedited basis to applicants, who can be public or private non-profit agencies. Applicants must show that their program is consistent with the overall state HIV plan, and that those tested will be referred to appropriate community services. Funds may be used for both the testing itself and for aggressive outreach and advertising of the program in the target population.

6–9 Where anonymous testing services are offered, the appropriate state or local health authorities should assure that the services are consistent with those offered at other sites, including full access to partner notification assistance and reporting data generated into seroprevalence monitoring systems.

6–10 State laws should not prohibit private laboratories from performing HIV analysis.

Section II. Partner Notification

Both public health practice and case law makes clear that persons put at risk of exposure to an infectious disease should be alerted to their exposure. The Commission believes that there should be a process in place in every state by which the official state health agency is responsible for assuring that those persons put unsuspectingly at risk for HIV infection are notified of that exposure. Such a process will enable that agency to work with the infected individual and the patient's primary health care provider to assure that contacts are notified of their exposure and urged to take advantage of the opportunity for testing and counseling.

When interviewed appropriately, any person infected should be able to identify one or more persons from whom the infection may have come or to whom it may have been given. There are options for contacting those persons and ensuring that they, too, are aware of their risks. Those options include patient-managed referral and professional-assisted referral (with notification by an individual's health care provider or with notification by the health department).

Though the ideal would be to attempt to locate every sexual partner of every individual who tested HIV antibody positive, this is not realistic for most partner notification programs. Some states have already instituted partner notification, which is labor-intensive in nature. In light of limited public resources, they have established a priority list for partner notification. As an example, consider the woman who has been married for 30 years to a man who, unknown to her, is a bisexual, or the person who believes he or she is involved in a completely monogamous marriage when, in fact, his or her spouse has been having sex with others. These people are completely ignorant of their exposure to the virus and would probably remain so until either their spouse, their child, or they, themselves, developed the clinical symptoms of AIDS. The Commission firmly believes in these individuals' right to be notified of their possi-

ble exposure so that they can seek prompt medical attention and avoid potentially exposing others.

Those states which decide to fully fund partner notification as a major initiative to intervene in the HIV epidemic should consider also efforts to notify paraphernalia-sharing partners of intravenous drug abusers, preferably through training drug abuse treatment providers in partner notification procedures and then through increased funding for the purpose. Such an effort, however, should be considered only in addition to intensive efforts to notify sexual partners.

In keeping with the long tradition of the public health profession in respecting, in a confidential manner, both data and affected persons, the need to report identities should not be a bar to partner notification or to persons coming forward for testing. It is critical, however, that in proposing and implementing partner notification, the public health authorities involved must stress the confidential nature of the process and build confidence in those affected. Furthermore, there would be no purpose in public health authorities informing the notified partner of the identity of the person who disclosed the partner's name; this standard operating policy of traditional partner notification procedures should be followed also with respect to HIV.

Obstacles to Progress

- Difficulty exists in appropriately reconciling conflicts between rights of partners to notification and codes of medical ethics which have long and appropriately asserted that communications between doctors and patients are privileged and that doctors must maintain the privacy of patient communications.

- Many health care providers are neither skilled nor trained in providing the necessary counseling that is an integral part of partner notification.

- The application of traditional partner notification practices to this epidemic has been slow for a number of reasons, including: the lack of a cure which could be offered to the infected partner, unlike the case with other sexually transmitted diseases; the extreme fear of subsequent discriminatory retaliation; the limited resources available for HIV prevention services; and the perceived high cost per case for partner notification programs.

RECOMMENDATIONS

6–11 Any HIV-related confidentiality law should provide for confidentially reporting identity-linked test results to public health authorities.

6–12 Each state public health law should protect the confidentiality of an individual's reported infection status but allow for partner notification without informing the contacted partner of the identity of the infected person.

6–13 All state and local health agencies should initiate and be funded adequately to develop HIV partner notification programs without diverting resources from other sexually transmitted disease partner notification programs. These programs should include counseling, testing, and supportive follow-up for those individuals who are notified of their possible exposure.

6–14 To assure maximum use of resources, partner notification programs should be prioritized. Partner notification should begin with the partners of the following persons:

- hemophiliacs.
- persons who have received contaminated blood or blood products identified through "look-back" notification programs and other means.
- rejected military applicants.
- bisexual males.
- intravenous drug abusers.
- persons with multiple sex partners.
- persons with anonymous sex partners.
- infected prison inmates.

6–15 The public health department has an obligation to ensure that any partners are aware of their exposure to the virus. The public health authority and the primary provider should determine the priority of follow-up, the nature of verification that warning occurred, and the role of the identified individual in notification by considering such factors as:

- the patient's own statements, including commitment to provide notification directly.
- the patient's relationship with the party.
- the potential additional risk presented by a delayed notification.
- evidence that the third party is aware of the risk.

- the strength of the physician-patient relationship.
- other relevant factors.

6–16 Continuing education programs and the policies and programs of professional organizations should emphasize and reinforce the role of the public health authority and the ethical obligation of each health care provider to participate in the reporting process and partner notification programs, as well as include the scientific and behavioral information about the transmission of the virus.

Section III. Restrictive Measures

The primary focus in developing a comprehensive public health strategy to control HIV infection should be placed on those public health measures that are based on voluntary cooperation in risk-reducing behavior change: focused education; voluntary testing; counseling; partner notification; and treatment for drug abuse. However, these prevention measures even vigorously applied will be unsuccessful in persuading some small number of individuals to alter their behavior. When an individual poses a health risk to others by remaining noncompliant with recommended behavior change, appropriate control measures should be employed to achieve the public health objective of controlling the spread of HIV.

Compulsory control measures are usually authorized in state public health laws and could include limited isolation or supervised living arrangements. Such measures restricting the activities of individuals are appropriate to clearly culpable conduct that poses a significant risk of transmission when narrowly applied with adequate procedural safeguards. While a few states have amended their public health laws to permit some form of isolation with respect to HIV-infected individuals, the absence of a range of less restrictive compulsory measures and procedural deficiencies in many state public health statutes make it essential that states update these laws before employing them as a response to recalcitrant individuals.

Obstacles to Progress

- Traditional public health quarantine is not well suited to the limiting of HIV transmission.
- Many state public health statutes are deficient because of: basic structural problems caused by artificial boundaries erected between venereal and communicable diseases; the absence of clearly stated, objective criteria to guide public health officials in the exercise of their powers; the absence of procedures necessary for fair and impartial public health decision-making; and the absence of a range of less restrictive powers sufficiently flexible to allow supervision in the community.
- Public health officials and other interested groups fear that excessive attention to personal control measures may undermine public health goals by diverting attention and resources from effective prevention policies such as education, testing, counseling, and partner notification.
- Many people confuse public health restrictions designed to stop further spread with punitive measures intended to retaliate for past exposure of others.

RECOMMENDATIONS

6–17 States should immediately reform existing public health statutes designed to control the spread of communicable diseases according to the following guidelines:

- Rigid distinctions between venereal and communicable diseases should be removed.
- The public health statute should specify that use of personal control measures must be based upon a finding that the person is in an infectious state and is reasonably likely to transmit the infectious agent, posing a serious risk to the public health.
- The public health statute should allow for a range of control measures, imposing on the infected individuals requirements such as: to report all changes of address to the public health department; to attend sessions at appropriate places and times for the purposes of education, counseling, testing, medical examination or treatment; and if necessary, to be admitted to a hospital, detoxification center, or a clinic for treatment of drug dependency or sexually transmitted disease on an out-patient or day-patient or in-patient basis. Control measures should have the same procedural safeguards and enforcement should be for a specified period of duration.
- The statute must provide procedural safeguards of written notice, counsel, presentation of evidence and cross-examination, a clear and convincing standard of proof, and a verbatim transcript for appeal (the procedural safeguards required in civil commit-

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ment of the mentally ill). An impartial decision-maker should hear the case prior to, or in cases of urgent necessity, immediately after the imposition of personal control measures. A process for review of the decision must be authorized. Due process must be accorded.

- State public health statutes should include strong uniform confidentiality protection.

6–18 Quarantine or isolation of HIV-infected individuals based only on HIV status without consideration of an individual's behavior is not appropriate and should not be adopted.

6–19 Less restrictive measures under public health laws should be exhausted before more restrictive measures, such as limited isolation, are taken.

6–20 In exercising powers of isolation under public health laws, there should be a heavy burden on the public health official to determine that these are necessary and appropriate and that a factual basis exists for making a determination to isolate.

Section IV. Safety of the Blood Supply and Donated Tissue

As of June 6, 1988, 2,399 of the people diagnosed with AIDS had acquired the infection through transfusions of blood, blood products, or the clotting factors used to treat hemophilia. The initial response of the nation's blood banking industry to the possibility of contamination of the nation's blood by a new infectious agent was unnecessarily slow. However, important lessons were learned from this chapter of our blood banking history which cannot be dismissed as we face future problems. The Commission believes strongly that the blood banks should not delay any longer the screening for another blood-borne virus, HTLV-1, which is believed to be the cause of adult T-cell leukemia/lymphoma and a severe neurological disease known as tropical spastic paraparesis (TSP).

Technological advances in blood screening tests and the purification process of the clotting factor have rendered the nation's blood supply as safe as it ever has been; however, this does not imply that it is completely free of risk. Transfusions of blood can be lifesaving, but it must be remembered that their side effects can cause serious illness or death.

The most significant complications of blood transfusions are immunologic reactions and the transmission of infectious disease agents, including the transmission of HIV. While donor screening procedures combined with pre-transfusion laboratory tests can reduce the incidence of the transmission of diseases such as hepatitis, syphilis, malaria, and HIV, they cannot eliminate the risk.

It is for these reasons that the Commission supports aggressive screening of the nation's blood donors along with thorough testing of the blood that is donated. However, the surest preventive measure with regard to the blood supply is to eliminate the exposure of a patient to the blood of others, whenever possible.

The same principles apply to donated organs and semen. An organ or semen that has been infected with HIV can transmit that infection to the recipient. The same type of infection control that is practiced with the blood supply needs to be applied equally to organ transplants and artificial insemination.

Obstacles to Progress

- Many physicians and hospitals do not have an adequate understanding of and, therefore, have not adequately informed their patient population about the availability of alternatives to traditional transfusion therapy.

- Because a majority of the fresh blood supply is derived from voluntary donations, the blood banking industry must actively recruit numerous donors into the system. As many donors as possible are accepted.

- The Food and Drug Administration (FDA) has the responsibility to set the standards for the blood industry; however, it relies heavily on that industry for advice on what standards to set -- a relationship that presents a significant opportunity for conflicts of interest to arise.

- Health care financing plans that are applied to traditional homologous transfusion therapy often cannot be applied to autologous transfusion therapy.

- Some regional blood centers have been hesitant to promote strategies that minimize the use of transfusion therapies, since their operating income is derived from the sale of blood and blood products.

- Not all facilities have instituted notification procedures for those persons transfused with blood or its components since 1977. Not only persons

transfused but also their sexual partners may have been exposed to infection.

- Blood banks are currently using a self-deferral system whereby those individuals who have practiced behaviors that put them at greater risk of becoming infected with HIV are encouraged not to donate blood. Because this is an entirely voluntary process, some individuals who are at greater risk of HIV infection continue to donate blood despite attempts to exclude these individuals from the donor pool.

- Because of the significantly increased workload that the HIV epidemic has presented and the lack of human and financial resources, manufacturers of blood screening tests have an extremely limited access to FDA review staff. This slows the introduction of useful new screening products to the market.

- Recent advances in technology have made clotting factors safer. However, the application of such technology has resulted in a four- to eight-fold increase in cost to the patient. This substantial rise in cost has resulted in considerable concern that third-party payments could be jeopardized and access to such products denied.

RECOMMENDATIONS

6–21 As soon as is practically possible, but no later than July 1, 1989, agencies which license and certify health care facilities should make a condition for licensure, a program to notify all recipients of blood or blood products since 1977 of their possible exposure to HIV. Such "look-back" notification should include a statement about the benefits of receiving counseling and testing services and provide information about where such services are delivered. This may be done in conjunction with local or regional blood banks or the state or local health department. Notification of partners of these persons is the responsibility of public health agencies. If licensing agencies do not take such immediate steps, Congress should then enact a law that requires it.

6–22 Informed consent for transfusion of blood or its components should include an explanation of the risks involved with the transfusion of blood and its components, including the possibility of HIV infection, and information about appropriate alternatives to homologous blood transfusion therapy. These specifically include pre-deposit autologous blood, intra-operative autologous transfusion, hemodilution techniques, and post-operative collection.

6–23 The Food and Drug Administration, in an effort to ensure that the nation's blood supply is never contaminated, should define a mechanism that quickly identifies a new threat to the safety of the blood supply and implements procedures that will abrogate that threat.

6–24 The Food and Drug Administration, in collaboration with the Blood Products Advisory Committee, should identify principles on which to base the introduction of new testing requirements and actively assess additional direct or surrogate tests in order to consider their introduction. Surrogate tests, such as serology for syphilis, should be required.

6–25 The Food and Drug Administration (FDA) should restructure the membership of its Blood Products Advisory Committee so that it reflects the entire blood products community, the plasma industry, and members of the related academic community, as well as one or more public members. In its capacity as an advisory body to FDA, this Committee should actively monitor advances in research and development and recommend changes in policy and practice that should be implemented by the blood industry which will promote the further safety of the blood supply.

6–26 In health care facilities, all reasonable strategies to avoid homologous transfusion (blood from others) should be implemented including pre-deposit autologous transfusions, hemodilution techniques, intra-operative autologous transfusions, and post-operative collection. Health care facilities should offer aggressive in-service training to their staff, particularly blood banking and transfusion services personnel, to bring them up-to-date on current autologous transfusion therapy techniques.

6–27 The Health Care Financing Administration and the Health Resources Services Administration working with the National Hemophilia Foundation should develop alternative payment mechanisms to make clotting factor treatment affordable for patients.

6–28 The Centers for Disease Control should make grants available to Comprehensive Hemophilia Treatment Centers to be used for the design and implementation of risk-reduction and psychosocial support programs. The objectives of such programs should be to educate HIV-infected hemophiliacs about techniques to

avoid the further transmission of the virus either sexually, perinatally, or through the sharing of needles.

6–29 All blood banking facilities should implement screening procedures to identify the presence of HTLV-1 in the homologous blood supply.

6–30 The Food and Drug Administration (FDA) should fund an independent scientific organization to initiate a six-month study of the extent, purpose, and effectiveness of existing blood donor registries and the effect that expansion and/or requirement of donor registries would have on the safety of the blood supply. The independent organization should report the results of such a study to both FDA and the Congress.

6–31 Health care financing plans should treat autologous transfusion therapy no differently than homologous transfusion therapy. Coverage should apply to both.

6–32 All states should immediately enact legislation requiring the registration of facilities for the collection, storage, and transfusion or administration of blood, organs, other tissues, semen, and breast milk, in order to facilitate enforcement of regulations requiring screening for HIV.

Section V. Laboratory Quality

The HIV antibody tests now available are reliable when performed under well-supervised conditions in excellent laboratories. The consequences of poor quality control in the laboratories that perform diagnostic tests can have devastating effects on people's lives. This problem is brought into especially sharp focus by the consequences of a misdiagnosis of HIV infection due to disorganized laboratories. This applies to all laboratory tests, not just those for HIV.

Continued public awareness of this situation discourages individuals from seeking HIV testing and community groups from recommending testing. Currently, there are 98,000 unregulated physician laboratories in the United States. Only 16 states regulate these physician laboratories. There are 37 states that regulate independent laboratories and 40 states that regulate the labs in hospitals. There is no standard regulation policy among even these. FDA regulates laboratories that engage in interstate commerce and the Health Care Financing Administration regulates laboratories that bill Medicare or Medicaid for services.

The initial screening test for HIV, known as the Enzyme-Linked Immunosorbent Assay (ELISA), is a relatively simple test to perform and interpret. Because the ELISA is more sensitive than it is specific, however, any positive results from an ELISA screen need to be confirmed by a more specific test before they can be trusted. The most commonly used confirmatory test is a Western Blot Assay (WBA), a more complex -- and expensive -- test whose performance is currently limited to a relatively few laboratories.

It is critical that laboratories performing WBAs and/or other sophisticated confirmatory tests employ highly skilled technicians and stringent quality standards, since it is the confirmatory test result that is definitive to diagnosis. The HIV antibody tests are extremely accurate, and false positives are no longer a problem when repeatedly positive ELISA screening tests are followed with the confirmatory Western blot tests done in qualified laboratories. Therefore, we suggest that FDA and CDC in cooperation with other government agencies consider capabilities for the confirmatory HIV antibody testing.

This could be done by sending "known" tests to certified confirmatory HIV antibody testing laboratories at intervals to check their personnel for accuracy. Any laboratories having unacceptable clerical mistakes or other personnel errors could face a problem in maintaining their continued certification.

Obstacles to Progress

- Many labs in the United States have no outside review of quality.
- The Health Care Financing Administration has reduced the number of its laboratory inspectors by 30 percent.

RECOMMENDATIONS

6–33 The Health Care Financing Administration, the Centers for Disease Control, the Food and Drug Administration, the National Governors Association, and the Association of State and Territorial Health Officials should develop a model state laboratory licensing law that addresses: types and levels of tests performed; personnel standards; use of proficiency tests; on-site inspections; and participation in education programs.

6–34 The Public Health Service should provide funds that will enable states to implement the above model law.

6–35 The Food and Drug Administration should impose criteria at least as stringent as the model state law on laboratories involved in interstate commerce.

6–36 The FY 1989 allocation for the Health Care Financing Administration should be increased so that it can expand its laboratory inspection efforts.

6–37 Medical professionals and laboratories should immediately adopt the policy of not reporting positive initial screening test results (such as ELISA) to the tested individual or to public health authorities without first having confirmed such positive results by a Western Blot Assay or other approved test.

6–38 Performance of the Western Blot Assay or other confirmatory tests should be restricted immediately to laboratories which currently meet high quality standards, and priority should be given to assessing labs currently doing such tests for possible certification to continue their practice.

6–39 Consideration should be given to contracting out laboratory assessment activities to professional organizations experienced in evaluating laboratory quality.

Section VI. Therapists' Role in Prevention

Professional therapists and counselors (such as marriage, family, and sex therapists, psychiatrists, psychologists, pastoral counselors, social workers) are an underutilized resource in the HIV epidemic. They play four major roles in prevention:

- counseling those who are infected on how to avoid spreading the disease to others;
- counseling their general patient population, most of whom are not infected, on how to avoid becoming infected;
- encouraging self responsibility and social responsibility; and
- test-linked counseling.

Obstacles to Progress

- The therapists' role in prevention has been generally overlooked.
- Many professional associations have not recognized or encouraged their memberships to serve this function.
- Qualified counselors to perform post-test counseling are in short supply.
- Funding for post-test counseling is not adequate.

RECOMMENDATIONS

6–40 Therapists and counselors should counsel their patients/clients who are participating in behaviors that make them vulnerable to infection with HIV with the purpose of behavior modification.

6–41 Therapists and counselors treating HIV-infected patients/clients should encourage sexual and social responsibility.

6–42 Therapists and counselors should be encouraged to become well-informed and up-to-date on HIV infection. Professional associations should be encouraged to provide this education.

6–43 Incentive programs and grants should be developed to create and attract more qualified counselors to perform test-linked counseling.

6–44 Therapy and counseling associations should cooperate in establishing an interdisciplinary advisory committee to develop guidelines for therapists on advising their patients about protecting themselves, their partners, and their unborn children from infection.

CHAPTER SEVEN: EDUCATION

It is critical that the term "education," when used in conjunction with the HIV epidemic, is not associated only with a formal setting such as the classroom. HIV-related education needs to take place in all locations, both within and outside of society's mainstream. Education about HIV needs to occur both inside and outside of our nation's schools and workplaces. No corner of society can be neglected as educational programs about the HIV epidemic are developed and implemented. The Commission recognizes the vital role that health care workers occupy in meeting the educational needs of our society as a whole. Their own, unique educational needs are addressed in the chapter on patient care. The responsibility of employers to provide the nation's work force with general health information, including information about HIV, is addressed with other workplace issues in the chapter on societal concerns. This chapter will address those educational strategies that can be implemented for the rest of society.

During the last year, there has been a great deal of sometimes acrimonious debate over the content of HIV education. The Commission is concerned that, in the promotion of the personal moral and political values of those from both ends of the political spectrum, the consistent distribution of clear, factual information about HIV transmission has suffered. HIV education programs for example, should discourage promiscuous sexual activity and recognize the benefits of abstinence and monogamy; however, they need to be explicit in nature so that there is no confusion about how to avoid acquiring or transmitting the virus. The Commission firmly believes that it is possible to develop educational materials and programs that clearly convey an explicit message without promoting high-risk behaviors. All HIV education programs should emphasize personal responsibility for one's actions. Actions have consequences.

No citizen of our nation is exempt from the need to be educated about the HIV epidemic. The real challenge lies in matching the appropriate educational approach with the people to be educated. It is not the role of the federal government to dictate to local communities their values, and too much time has been wasted on this debate when educational materials are needed which clearly present the facts about AIDS and HIV transmission. In a similar vein, those who seek to use HIV education programs to further their own ideology of whichever stripe cannot expect federal funds for this purpose. In short, the federal, state, and local governments should convey the current medical and scientific facts to the American public and they, in turn, will build curricula suited to their own community value systems. When these curricula are constructed well, with all responsible local entities working in a collaborative way to help ensure their efficacy, the educational response of one region of the country can be expected to differ from that of another. Both responses should be applauded.

The Commission believes that several education initiatives are of such vital importance to the effective preventive management of the HIV epidemic that they must be implemented immediately. These include: general public education, distinct population targeting, and school-based education.

Obstacle to Progress

- The educational response to the epidemic in many areas can best be described as haphazard. There is often a lack of statewide planning that

involves input from local health departments, community-based AIDS service organizations, schools, philanthropic organizations, religious institutions, and other appropriate voluntary initiatives.

RECOMMENDATIONS

7-1 All HIV programs should emphasize personal responsibility for one's actions. Actions have consequences.

7-2 State departments of health should assume the lead responsibility for coordinating HIV-related educational initiatives within each state. State departments of health should develop a one-year plan and a five-year plan that clearly define the state's educational response to the HIV epidemic. Such a plan must include the input and identify the roles and responsibilities of local health departments, professional health care associations, community-based AIDS service organizations, state and local education agencies, philanthropic organizations, religious institutions, and other appropriate voluntary initiatives. The one-year plan should be developed by September 1, 1988 and the five-year plan by January 1, 1989.

Section I. General Public Education

In a national response to an epidemic, there is some information which every citizen should receive regardless of race, sex, age, geographic location, literacy level, or degree of risk for infection. This information sets the tone for more specific education and prevention programs and helps sustain our community effort as a whole. General information about the HIV epidemic should include basic facts about HIV infection and AIDS, the ethical obligation to be both non-discriminatory and caring, and resources where a person can obtain more detailed information.

The Role of the Media

The media, both electronic and print, have a tremendous opportunity to enhance the public's knowledge and attitudes about the HIV epidemic through the information that it chooses to present. There have been many examples of responsible -- and unfortunately some examples of irresponsible -- reporting and programming on the HIV epidemic. The Commission realizes that media activity alone cannot bring about positive behavior change; however, it can support the education activities of a community by providing constant, accurate information about the epidemic.

Obstacles to Progress

- Inaccurate or incomplete information about the HIV epidemic is, at times, presented by the media, both in their entertainment and news activities.
- Public service announcements are often broadcast at times when a majority of the population are not watching television or listening to the radio.
- Media events, such as a special program about the HIV epidemic, public service announcements, or a news story, often are not coordinated with state or local health departments or community-based organizations, resulting in an unexpected high demand for services or information which cannot be met because of lack of notice.
- The entertainment industry often portrays promiscuous sexual activity and drug use in a glamorous light and fails to mention the frequent negative consequences of such activity.
- Geographically specific HIV infection data and other related information are not available to the media in all parts of the country.

RECOMMENDATIONS

7-3 The electronic media should schedule a majority of its HIV-related public service announcements at times when they will receive high visibility.

7-4 The Centers for Disease Control should create a weekly newsletter targeted specifically to the media that provides accurate, current information about the HIV epidemic, including data as geographically specific as possible. Such a newsletter should include a telephone number that can be called during regular business hours to receive the most up-to-date information about the HIV epidemic. Such a newsletter should be widely advertised through trade journals, conferences, and other appropriate avenues, and should be offered on a subscription basis at reasonable cost.

7-5 State and local health departments and community-based AIDS service organizations should sponsor seminars for members of the local news and entertainment media. The seminars should help coordinate activities, provide current and accurate information about the HIV epidemic, and explain HIV-related services that are being offered throughout a community or state.

7-6 The entertainment industry should portray irresponsible sexual and drug-related activity in a manner that reflects the potentially detrimental emotional and physical consequences of such behavior and should shift focus to presenting the appeal of healthy behavior.

7-7 The Centers for Disease Control (CDC) should conduct a 90-day study on the effectiveness of purchasing paid advertising, in addition to requesting advertising at no cost, to present information about the HIV epidemic to the general public. If the study concludes that such a purchase would be effective, CDC should purchase paid advertising.

The National AIDS Hotline

The National AIDS Hotline operated by the Centers for Disease Control (CDC) serves an important function in providing the general public with a toll-free telephone number that can be called 24 hours a day. The Hotline counselors can provide the caller with general information about the HIV epidemic, answer specific questions, provide information about HIV-related services that are available within a specific community, and take requests for publications offered by the National AIDS Clearinghouse. The Hotline offers one of the greatest opportunities to provide educational information in a professional, confidential, direct manner to any member of the public.

Obstacle to Progress

- Many citizens, including those most at risk of HIV infection, are not aware of the National AIDS Hotline and the services it offers.

RECOMMENDATIONS

7-8 The Centers for Disease Control (CDC) should aggressively market the National AIDS Hotline through its ongoing HIV education and information campaign. The toll-free number, along with a description of services offered, should be widely publicized in informational pamphlets and public service announcements that are sponsored by CDC.

7-9 The National AIDS Hotline should continue to offer 24-hour counseling to respond to the needs of any caller. The Centers for Disease Control should ensure that there are sufficient operators on duty at all times to meet demand.

7-10 The Centers for Disease Control should equip the National AIDS Hotline with communications capability for the hearing impaired by August 1, 1988.

7-11 The National AIDS Hotline should serve as a referral center for the following services: community-based service organizations, advocacy and protection programs and services, availability of drug and vaccine trials, counseling and testing centers, and federal, state, and local agencies that deliver HIV-related services.

The National AIDS Clearinghouse

The National AIDS Clearinghouse operated by CDC is intended to tell the public where pertinent information about the HIV epidemic can be obtained. It has also been described as a resource for public health officials and health care providers.

Obstacles to Progress

- The only general information publications that the National AIDS Clearinghouse currently offers are those documents produced, either directly or under contract, by the federal government.
- The National AIDS Clearinghouse has not been connected with the existing electronic network that serves state and local public health departments.

RECOMMENDATIONS

7-12 The National AIDS Clearinghouse should continue to make available free of charge those documents pertaining to the HIV epidemic produced by the federal government.

7-13 The Centers for Disease Control (CDC) should conduct a potential user survey of state and local departments of health, community-based service organizations, and individual practitioners to determine their information requirements. At the conclusion of the survey, CDC should then ensure that the clearinghouse has the necessary funding and direction to meet those requirements.

7-14 The National AIDS Clearinghouse should collect and disseminate educational materials, including curricula and methods of instruction related to both the medical and the societal aspects of the HIV epidemic that are produced by federal, state, or local agencies or community-based service organizations. The Clearinghouse should make a catalog of these materials available free of charge, and provide copies of such material on a fee-for-service basis.

7-15 The National AIDS Clearinghouse should collect and actively disseminate to education associations, chief state school officers, school districts, and others school-based educational materials, including sample curricula and methods of instruction concerning the HIV epidemic. The Clearinghouse should make a catalog of these materials available free of charge, and provide hard copy of such material on a fee-for-service basis.

7-16 The National AIDS Clearinghouse should make federally produced documents available in braille and on audio cassette.

7-17 The National AIDS Clearinghouse should become connected with the electronic information networks that serve state and local departments of health.

Section II. Distinct Population Targeting

While the HIV epidemic affects all segments of society, it is important to recognize that each distinct segment has its own unique educational needs. The Commission recognizes that it is behavior, not membership in any particular group or population, that places a person at greater risk for HIV infection. However, the educational response to the epidemic needs to acknowledge the eclectic nature of our society and effectively match the proper educational approach with a receptive target population.

The Commission has heard testimony from members of many different distinct populations, including homosexual men, blacks, Hispanics, students, advocates for runaway and homeless youths, the hearing-impaired, and advocates for the developmentally disabled. But for all these groups, or for any other distinct population, the principles involved in the development of curricula and methods of presentation are the same. The design and implementation of educational programs must have significant input from members of the targeted population so that each program will be relevant, appropriate in language, and effectively reach the intended audience.

State and local public health departments, in conjunction with community-based AIDS service organizations and other community leaders, are in the best position to understand the cultural, language, lifestyle, educational, and behavioral components of their communities. It is because of this understanding that the assessment of the education needs of a community must occur at the local level, reflecting local community values.

Following that assessment, local communities must develop and implement comprehensive HIV education strategies that will meet the community's specialized needs. However, local communities will not be able to meet their prevention and education needs without significant financial and technical support from both the state and federal governments and the private sector.

Obstacles to Progress

- Comprehensive, integrated strategies developed by state and local departments of health in conjunction with community-based organizations often do not exist, resulting in the duplication of some services and the absence of others.
- Community-based organizations often lack expertise in program development, management, and grant writing.
- National information and education campaigns implemented to date have not been significantly targeted to -- and therefore do not reach -- distinct populations, such as minority communities.
- The basic health care needs, including education and prevention programs, of minority populations have not been met in the past, a situation that is being compounded by the HIV epidemic.
- Federal, state and local funding of community-based initiatives has been scarce and uncoordinated. As a result, communities have been unable to develop and implement adequate long-term prevention and education services.
- Funding patterns have not enabled community-based education initiatives to be adequately evaluated by their sponsors, making it difficult to design further programs with any certainty that they will be effective.

RECOMMENDATIONS

7-18 The Centers for Disease Control (CDC), in conjunction with the Public Health Service Office of Minority Health, should increase its information and education programs targeted toward minority communities. In so doing, CDC should contract directly with minority advertising agencies and community-based service organizations to develop a media-based information and education campaign including the input from the community-based service organizations targeted toward specific minority populations in

10 metropolitan areas that have significant minority populations. CDC and the Office of Minority Health should choose those 10 cities. The content of such a campaign should be clear and unequivocable and culturally relevant to the communities. CDC should be responsible for the content of such a campaign and the advertising agencies should be responsible for determining the most effective way to package and deliver that information. The major objective of such a media campaign should be to inform people about activities that place them at risk of becoming infected with the virus and to identify HIV-related services that are available within a specific community. The result of this media-based minority information and education initiative should be the creation of model media-based public information programs that can be easily replicated in other parts of the country. Consideration should be given to use of extended presentations, not just spot announcements.

7-19 Once such a media-based campaign has been developed, the Centers for Disease Control should make funds available to state and local departments of health so that targeted paid advertising can be purchased in media outlets specific to minorities and other distinct populations. Such funding should reflect the need to present paid programs, not just spot announcements.

7-20 When federal money is used to finance all or a part of an educational program, the Centers for Disease Control should ensure that all program sponsors have a detailed evaluation component included in the program that measures, among other indicators, changes in behavior, knowledge, and attitudes pertaining to the HIV epidemic.

7-21 State and local departments of health should recognize the disproportionate way in which the HIV epidemic has affected minority populations. They should, at a minimum, allocate a percentage of their HIV prevention and education budgets directly proportional to the minority populations within their jurisdiction for the delivery of prevention and education programs to those minority populations. State and local departments of health should ensure that all educational programming produced is linguistically relevant to the targeted audience.

7-22 State and local departments of health should ensure that easily accessible HIV-related services, including public health education programs, peer counseling, and other risk reduction interventions, are being offered within their jurisdictions.

7-23 The Centers for Disease Control, states, and localities should increase funds to state and local health departments to initiate and/or increase HIV prevention and education activities. These activities should include public health education campaigns, peer counseling, outreach education, and other risk reduction interventions.

7-24 The Centers for Disease Control (CDC) in conjunction with states should increase funds and technical assistance in program development, management, and fundraising (including grant writing) to community-based service organizations so they can develop appropriate prevention programs. These programs should include public health education campaigns, peer counseling, outreach education, and other risk-reduction interventions. Where federal money is involved, CDC should require that all grant applicants include detailed evidence of their ongoing coordination with state and local departments of health.

7-25 Because community-based organizations have successfully used their credibility with hard-to-reach populations to bring their educational messages to a broad audience, state and local health departments should provide support to responsible community-based organizations providing such services.

7-26 All citizens and philanthropic groups should be challenged to target at least a portion of their activities over the next 10 years to programs and services which will further reduce the risk of HIV transmission. Economic and political realities make it impossible for public funds to support all possible activities related to control of HIV infection. Public funds will only sustain basic services and may not be able to provide the specificity needed by some groups. Private support can extend the services and can experiment creatively with new approaches.

7-27 The Department of Health and Human Services (HHS), the Department of Housing and Urban Development (HUD), and states should increase funds to national and local organizations that

provide services to homeless and runaway youth. The funds should be used to initiate and/or expand programs designed to provide appropriate education strategies for runaway and homeless youth. When federal money is involved, HHS and HUD should require that all recipients provide detailed evidence of ongoing coordination with state and local departments of health and other social service agencies. Funding should be based on an established history of positive interventions with homeless and runaway youth and innovative program design.

7-28 The Centers for Disease Control should make funds available to organizations representing persons with disabilities and special education professionals to develop materials and disseminate information about HIV infection. Such materials should be targeted to the unique needs of individuals with mental retardation, mental illness, hearing impairments, visual impairments and other learning and physical impairments.

7-29 The Centers for Disease Control should make evaluation grants to state departments of health to conduct special studies to determine what programmatic interventions are most effective in reducing transmission of the virus in various communities. Detailed information about those programs, including program content and implementation strategies, should be provided to other state and local departments of health, as well as national and community-based AIDS service organizations, so that those programs can be replicated in other parts of the nation.

Section III. School-Based Education

The Near-Term Response: Immediate HIV Education

A two-part response to the epidemic is required from the nation's elementary and secondary school system. The first part must happen in the short term. It is the opinion of the Commission that the provision of HIV education in our schools is of vital importance and must be introduced across the nation immediately. Some states have already ensured that this is happening; the rest must follow their lead. The decisions about appropriate content and methods of instruction should be determined at the local level; however, both elementary and secondary school students should receive such education. Students must be provided with current and accurate information about the HIV epidemic that is appropriate for age so that they can make informed decisions about their behavior and avoid those actions that put them at risk for HIV infection. School-based education should highlight the benefits of character development, abstinence, and monogamy. By ensuring that appropriate education about the virus is provided in the elementary and secondary school system, we can help our younger generation avoid the tragedy we are witnessing today.

The second part is the long-term response, which will have a far greater pay-off when fully implemented; that is the introduction of a comprehensive health education curriculum for all grades K through 12. This broader topic is discussed later in this chapter.

Obstacles to Progress

- The HIV epidemic involves some of our most personal behaviors, and many find it difficult to incorporate information about the epidemic and those behaviors into a classroom program.
- Many communities still do not believe that the HIV epidemic is something that will ever affect them and, therefore, see no need to provide HIV-related education to their children.
- Funding that will allow HIV education programs to be delivered is not in place.

RECOMMENDATIONS

7-30 State boards of education should mandate that an HIV education curriculum with appropriate content for age be offered to all students at each schooling level (e.g., elementary, middle, and high school) throughout the state.

7-31 If such a system is not already in place, the state director of health and the chief state school officer in every state should establish a formal mechanism to exchange information about the HIV epidemic, including current technical information and model education programs.

7-32 School staff who deliver HIV education should receive extensive in-service education before they begin instruction. The content of the in-service education should be designed in conjunction with state education and health agencies. No member of the school staff should be forced to deliver education about HIV if