Developing a National HIV/AIDS Prevention Program Through State Health Departments

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Synopsis

The Centers for Disease Control (CDC) shaped the basic development and direction of the HIV/AIDS Prevention Program through technical support and financial assistance for State and local health departments and other organizations. Through this provision of support, CDC has responded to the course of the human immunodeficiency virus (HIV)-acquired immunodeficiency syndrome (AIDS) epidemic by creating programs to preserve the safety of the blood supply, by developing counseling and testing centers, by promoting "safer sex," by promoting health education and risk reduction, by evaluating existing services, by disseminating new technology, and by targeting new at-risk behaviors as the infection spread. Funding has also been used to respond to congressional mandates, evaluations of program effectiveness, and the National Academy of Sciences report, "Confronting AIDS: Directions for Public Health, Health Care, and Research."

THE CENTERS FOR DISEASE CONTROL (CDC) is responsible for the prevention and control of numerous diseases in the United States, including acquired immunodeficiency syndrome (AIDS). A crucial mission of CDC's National Center for Prevention Services (NCPS) is to prevent the spread of infection with the human immunodeficiency virus (HIV), the virus that causes AIDS. NCPS activities include consultation and collaboration with diverse organizations and support of both research and direct prevention initiatives. NCPS has focused primarily on providing technical and financial assistance for the HIV prevention activities of State and local health departments, and this paper describes how NCPS shaped the basic development and direction of the HIV/AIDS Prevention Program.

CDC made financial assistance available through various provisions of the Public Health Service (PHS) Act. Those provisions authorize a Federal response in emergency situations and support kindred activities such as the prevention of sexually transmitted diseases (STDs). CDC used program announcements published in the Federal Register to describe program requirements and were guided in this by legislative mandates that emerged through the congressional appropriations process to define further the Federal role, in general, and the CDC role, in particular.

The epidemic of HIV-AIDS began in 1981 in the United States. From then until passage of the Health Omnibus Prevention Extension Act of 1989 and the Comprehensive AIDS Resources Emergency (CARE) Act of 1990, funding was appropriated under various sections of the PHS Act, including section 318, which authorizes STD prevention activities.

Licensing of the antibody test was a crucial event in the history of HIV-AIDS and for the national HIV/AIDS Prevention Program. The test permitted universal screening of donated blood and also allowed individuals to learn if they were infected. One major fear associated with the test was that persons with a high risk of infection might donate blood just to be tested. While many at-risk people had deferred blood donations, as was being recommended, both CDC and the blood banks recognized that preventing transfusion-associated infection would require that testing services be made available outside the blood bank setting.

HIV-AIDS Prevention Programs with States

The need to make HIV antibody testing services available outside of blood banks led to the first nationwide HIV- and AIDS-related prevention program, which was announced March 12, 1985, in the Federal Register (*1*). More than $10 million would be available for States to establish alternate sites where persons concerned about their infection status could go for testing. The funds for startup costs, which included those associated with labora-

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tory services, were reprogrammed from ongoing CDC activities, such as STD prevention and other PHS programs. (Since this first award of funds, CDC has continued to support the laboratory services component of all testing activities associated with HIV and AIDS.)

The alternate testing site program was a remarkable prevention effort. In 1985, only .04 percent of blood bank donations were positive for HIV antibody (*2*), whereas 17.3 percent (432 times higher) of volunteers tested at alternate sites were seropositive (*3*). These data demonstrate the success of State and local health departments in providing an alternative to blood centers for at-risk individuals to learn their antibody status.

A condition of funding ensured that anyone being tested received appropriate pretest counseling, posttest counseling, and referral for medical evaluation, if needed. While preventing contamination of the blood supply was the primary purpose of the alternate testing site system, CDC considered testing an adjunct to counseling. Public health professionals believed knowledge of one's antibody status could help motivate him or her to initiate and sustain behaviors to prevent infection. However, to do so required that the test prove accurate and the testing process include counseling for both the infected and those at risk of infection.

The data on which to test this belief soon materialized. By late 1985, CDC had affirmed that the recommended antibody testing sequence (repeatedly positive enzyme immunoassay confirmed by Western blot) yielded results with a very high predictive value for HIV infection. Since test results correlated highly with the presence or absence of risk factors in a person's lifestyle, CDC concluded that testing and counseling could be an important means of expanding prevention education to those at highest risk of HIV infection.

Consequently, in 1986, NCPS altered the basic focus of the alternate test site system by creating an extensive system of counseling and testing sites nationwide. Many freestanding sites still exist; however, many localities have integrated these services into STD clinics, family planning clinics, substance abuse treatment settings, tuberculosis clinics, and so forth. Serologic testing and intense counseling (individualized risk-reduction education), combined with partner notification to reach out to others most in need of such counseling, constitute the bedrock of NCPS's prevention efforts targeting those at highest risk for HIV–AIDS.

The fiscal year (FY) 1986 program announcement (*4*) clearly demonstrated the shift in focus concerning HIV antibody testing and counseling. In it CDC presented counseling about risk behaviors as a strategy intended to minimize the spread of the virus among sexually active persons, including gay and bisexual men. It also emphasized partner notification as an essential component of counseling. (CDC previewed this emphasis in a memorandum from the CDC Director to all State health officers on December 5, 1985, and in the March 14, 1986, Morbidity and Mortality Weekly Report.)

The new role of counseling in the evolving prevention strategy was evident in the stated purposes of the two initiatives and in the restrictions each placed on awarded funds. In 1985, for instance, NCPS specified that the funds were to be used only "insofar as is necessary to provide tests without charge for those who cannot pay." In 1986, however, NCPS specified that the purpose of funds was to help reduce the spread of HIV and to continue protecting the nation's blood supply.

Furthermore, the 1986 program announcement promoted the concept of "safer sex" as a prevention strategy. Given the lack of a medical intervention, the public health community needed to build a nationwide prevention strategy that focused on changing the behaviors known to transmit the virus. Prevention, noted the program announcement, "requires the promotion of sexual and lifestyle behaviors for individuals which will reduce their risk of acquiring and spreading the virus." Counseling was to include a discussion with the patient of "safer sex" as a part of the overall prevention strategy.

NCPS first supported the "safer sex" concept during a series of 44 one-day seminars in January 1985 to prepare States and local health departments for licensure of the antibody test. NCPS continued this emphasis during training courses held in May 1985 to prepare counselors who would staff alternate testing sites. (In January, 7,500 people in 34 cities attended the seminars; in May, CDC provided training for more than 500 State and local

personnel. An estimated additional 600 people were trained by State and local personnel using CDC curriculum, materials, and instructional design.) Participants learned what to tell persons who came for HIV antibody testing, at both pretest and posttest counseling sessions, for seronegative as well as seropositive results. NCPS disseminated protocols for HIV counseling through these courses, and PHS published broad guidelines for counseling and antibody testing in 1987 (*5*).

Health Education and Risk Reduction

NCPS required that the Counseling and Testing Site Program address specific prevention needs and provide risk-reduction education to those who sought testing. This program could not, however, fill all the educational needs created by this new disease. A small but active group of people and organizations that had been educating people about AIDS from the first days of the epidemic would be extremely helpful as CDC began trying to identify effective health education and risk-reduction strategies to reduce the spread of HIV.

Community-level education. In 1984, CDC initiated support of community-level education by funding the United States Conference of Mayors. This organization proposed giving small grants to emerging AIDS service organizations and publishing a newsletter advising mayors and local health officers of developments in the epidemic. In early 1985, NCPS provided funds to enhance the developing educational efforts in the five areas most affected by the epidemic. Health departments in San Francisco, New York City, and the States of Florida, New Jersey, and Texas split among them more than $1 million that NCPS again reprogrammed from operating funds.

By 1982, AIDS service organizations had emerged in many of the cities with a high incidence of disease. For instance, organizations such as the Gay Men's Health Crisis in New York and the San Francisco AIDS Foundation had evolved in response to AIDS. They responded primarily to the needs of patients with HIV disease and to the psychosocial needs of their families and friends. Most of the organizations with an AIDS-specific focus soon developed educational components. Some developed risk-reduction strategies—particularly those evolving from within the population most affected by the disease in its early years: white, homosexual, and bisexual men.

Evaluation. These local prevention efforts had not been evaluated in any formal way. However, in 1984, several cities with AIDS service organizations were reporting declines in the rates of rectal and pharyngeal gonorrhea among men ages 15–44. These declines coincided "with the period of heightened awareness and concern about the incidence of acquired immune deficiency syndrome (AIDS) among homosexual males" (*6*). The report motivated CDC to investigate the prevention efforts of some of the communities most affected by the disease.

In 1984, several teams of CDC personnel and consultants assessed ongoing AIDS-related health education and risk reduction activities in nine selected cities: San Francisco, Los Angeles, New York City, Miami, Newark, Chicago, Washington, Houston, and Atlanta. The teams' conclusions were compiled in an unpublished report ("Nine Cities Study," 1985) prepared by Professional Management Associates, Inc., Rockville, MD. The teams noted that most of the AIDS health education and risk reduction activities were being conducted by AIDS service organizations and that very little collaboration existed between State-local health agencies and community organizations with an AIDS focus.

The teams concluded that for AIDS health education and risk reduction to be effective, it must (*a*) target the lifestyle, language, and appropriate environment of a particular risk group and (*b*) have the collaboration of Federal, State, and local health agencies and community-based organizations representing the affected population.

These points would influence NCPS's emerging health education and risk reduction strategy, which was to forge collaboration between public health agencies and community-based organizations serving the interests of groups at risk for AIDS, and support development of interventions that, if effective, could be transferred to other programs. In addition, evaluation of interventions to demonstrate their effectiveness became a priority in NCPS's developing strategy.

Collaboration and technology transfer. Two program announcements that followed the 1984 study constituted important steps in NCPS's effort to develop the State-based HIV and AIDS prevention programs. Both emphasized collaboration and technology transfer of interventions to prevent the spread of HIV. The first announcement of July 1985 (*7*) would support community-based demonstration projects and innovative projects for HIV

and AIDS risk reduction. The second announcement (*8*), in January 1986, would support health education and risk reduction programs in the States.

Eligible applicants for the community-based demonstration and innovative risk reduction projects were State and local health agencies and other public or nonprofit private community organizations, educational institutions, or "other organizations that can demonstrate the capability to work in close cooperation with state and local health departments on the prevention and control of AIDS."

The expectation for both projects of the 1985 announcement was development and evaluation of theory-based interventions. The announcement noted that the lack of a cure or a vaccine for the disease made education the basis for HIV and AIDS prevention. It was acknowledged that gaps still existed in the understanding of risk factors for infection and specified that the purpose of the funding was to identify ways to persuade persons to take action to remain uninfected or prevent transmission to others if infected.

Both projects of NCPS's 1985 announcement supported community-level activities. The Community-Based Demonstration Project, for instance, sought the design, implementation, and evaluation of a program in a well-defined geographic or political subdivision of the recipient State. For both, the recipient of funding was to have assessed the knowledge, attitudes, beliefs, and behaviors of the at-risk population. Both required the recipient to share effective interventions with other agencies or organizations that were planning, implementing, or evaluating HIV and AIDS health education and risk reduction programs. NCPS hoped that this sharing would initiate the process of technology transfer that would be important to programs dealing with the HIV-AIDS epidemic.

Explicit guidelines. While CDC was responsible for the nationwide effort to prevent transmission of the virus, it recognized that the agency must also be accountable for the use of the public funds it allocated. Agency leadership held that both "safer sex" counseling and any materials used to explain the concept could prove objectionable in relation to some community norms. Thus, during 1985, NCPS developed guidelines on the explicitness of written and audiovisual materials, provided these guidelines to agencies approved for the Demonstration and Innovative Projects, and began the process of negotiating revised proposals. The January 1986 announcement contained the guidelines in the section, "Guidance—Content of Written Materials, Pictorials, Audiovisuals," which required the recipients of funding to establish local panels to review and approve the content of all AIDS-related materials used in a program. All subsequent HIV-AIDS prevention program announcements have carried this stipulation.

The guidelines evolved to incorporate later congressional stipulations that materials could not promote sexual behavior or drug use. Overall, however, the review process remains much as it was when it began. While the review process has produced some delays, few programs have experienced any interruption of activities because of public controversy over content.

Continued support. NCPS's continued support of both the demonstration and the innovative efforts, as well as those of the community-based activities in the cities with the highest incidence of AIDS, was clearly indicated by the announcement of January 1986; it made funds available for AIDS health education and risk reduction in following four specific areas:

1. State-based AIDS projects for community health education and risk reduction,
2. augmentation and evaluation of established health education and risk reduction in communities with a high incidence of AIDS,
3. community-based demonstration projects for AIDS prevention and risk reduction, and
4. innovative projects for AIDS risk reduction.

This announcement extended the Community-Based Demonstration and Innovative Projects; it also provided assistance to communities having a high incidence of AIDS and an ongoing community-based health education and risk reduction program, allowing these places first to intensify prevention efforts and then to evaluate them. The announcement also provided funding for State-based AIDS prevention programs.

State health departments could apply for all but the Innovative Projects, for which no new applications were accepted for 1986. State health departments that applied for both the State-Based AIDS Projects and the Augmentation and Evaluation Programs could be funded for only one of the applications. (In addition to State and territorial health departments, local governments that had reported 1,000 or more cases of AIDS could apply for Augmentation and Evaluation funding.)

In the State-Based AIDS Projects portion of the program, NCPS made available approximately $5.17 million to fund up to 45 new initiatives. The overall purpose of these initiatives was to develop and conduct programs to prevent HIV-AIDS. However, the specific purpose of the first year's funding was to assist States in building their capacity to deliver health education and risk reduction programs. Capacity-building would occur by providing the impetus to appraise community needs and resources related to the AIDS problem, to develop effective community-based organizations to implement the program, and begin actual implementation.

By directing funding through the program announcement, NCPS was formulating the details of the nationwide HIV and AIDS prevention program using the broad authorization set forth in appropriations language. The activities CDC required in this first year of funding for State health education and risk reduction projects would establish the foundation for all subsequent education carried out through the program.

National Academy of Sciences report. In late 1986, the National Academy of Sciences (NAS) and the Institute of Medicine (IOM) issued a joint report on the disease, "Confronting AIDS: Directions for Public Health, Health Care, and Research" (*9*). Its publication was an important event in the history of HIV and AIDS.

First, the report confirmed CDC's position that HIV-AIDS was a major public health problem. In 1986, many Americans viewed HIV-AIDS as a disease caused by one's lifestyle. Indeed, in its early years, it had affected primarily homosexual and bisexual men. While some who injected drugs were diagnosed with AIDS, the focus of media attention helped perpetuate a perception that AIDS was a "gay plague." The disease became entwined with various moral and political agendas, and it became increasingly difficult for many persons to see HIV-AIDS as an infectious disease. Consequently, there were segments of the general public and some public officials who did not support the use of public money to prevent HIV-AIDS.

Second, the report confirmed the direction that CDC had taken in trying to halt or slow the spread of the virus. It supported use of antibody testing and partner notification, and endorsed CDC efforts to target the behaviors that put people at risk. However, it criticized both NCPS's requirement that States establish local review panels and the vague content of public health references to sexual behaviors. While NAS called for the content of educational materials to be explicit, NCPS's position was that public controversy over prevention messages had the potential to defeat education efforts. The tension between these opposing perspectives characterized HIV-AIDS prevention efforts throughout the remainder of the 1980s.

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The report called for a major increase in the level of funding for all AIDS-related activities: education, serologic screening, surveillance, and research. Congress responded by significantly increasing the appropriations for AIDS education and research. In 1986, CDC was given the lead responsibility within the Public Health Service for HIV-AIDS education. New funding levels allowed the agency to expand its ongoing prevention efforts.

New target populations. The FY 1987 program announcement (*10*) made a major change in HIV-AIDS programs and initiated several new efforts. It consolidated the existing State-based HIV-AIDS projects. In addition, it specifically addressed the health education and risk reduction needs of black and Hispanic populations; school-aged youth; and medical, dental, and mental health providers.

Funding recipients were required to deliver information and health education and risk reduction services specifically to black and Hispanic populations and to involve representatives of these populations in the overall effort. This was to ensure a maximum level of awareness that they were disproportionately affected by HIV-AIDS, particularly perinatal AIDS, and of the need to consider measures to prevent the further spread of HIV. NCPS intended with this to effect a needed change of direction in State programs to address more promptly and forcefully the changing epidemiology of HIV-AIDS.

NCPS's program announcement significantly expanded the number of audiences targeted to receive prevention messages. For the first time NCPS asked State programs to address prostitutes, heterosexuals with multiple sex partners, and the sex and needle-sharing partners of those at risk (gay and

bisexual men and injected-drug abusers had been targeted in previous announcements). NCPS also focused on school-aged youth in 1987 and asked the States to promote a school program of high quality AIDS education that included sexually transmitted diseases (STDs) and substance abuse. In April 1987, CDC published two program announcements making funds available to support school health education to prevent AIDS (*11,12*).

NCPS's FY 1987 program announcement (*10*) also strengthened the evaluation component of health education and risk reduction projects by directing applicants to measure the effectiveness of their efforts. NCPS's evaluation component required that program objectives be specific, numerically measurable ones that specified the expected change that program effort would produce from the baseline levels of knowledge, attitude, and behavior regarding AIDS among risk groups, health care providers, and the general populations.

On August 7, 1987, NCPS published a program announcement (*13*) making supplemental funds available for the remainder of 1987. It made $27 million available to official health agencies that had been awarded support for testing and counseling in 1986 and prevention agreements in 1987. The funds were made available, in part, to ensure that HIV-AIDS activities would cause no further diversion of States' STD money. It also specifically directed $7 million toward health education and risk reduction activities among racial and ethnic minority groups.

The intent of the minority initiative was to strengthen NCPS's earliest efforts, that is, to forge collaboration between State AIDS prevention programs, community-based organizations, and AIDS service organizations. NCPS's program announcement (*13*) stated that minority community groups should be urged to collaborate with existing AIDS service organizations because of their invaluable prior experience and expertise in targeted AIDS education. Minority community groups contributed a needed identification and cultural sensitivity to the overall prevention effort. However, the program announcement also noted that the State program staff clearly have a role—for example, planning, coordination, consensus-building, the training of counselor-partner referral personnel in primary care centers.

Ongoing funding. NCPS FY 1988 program announcement (*14*) combined the surveillance and prevention programs. In it, NCPS sought to improve the completeness of AIDS case reporting, develop a national network of State case registries for AIDS, and require recipients of public funds to conduct epidemiologic investigations of cases having "no identified risk." In addition, this announcement funded seroprevalence surveys and studies being conducted by State and local health agencies representing 30 Standard Metropolitan Statistical Areas (SMSA). This was to help bring the surveillance and prevention components into a closer working relationship and to reduce paperwork associated with multiple grants.

NCPS FY 1989 program announcement was virtually identical to the 1988 announcement in detailing the activities of both CDC and the funds' recipients. The two differed, however, in their eligibility requirements. In addition, NCPS proposed in the 1988 announcement to fund the local public health departments in Los Angeles, New York City, and San Francisco for prevention and surveillance projects, when earlier NCPS had funded them for prevention only. NCPS also extended surveillance project funding for Baltimore, Boston, Chicago, Denver, and Philadelphia and limited funding for the ongoing seroprevalence studies in 30 SMSAs to those already participating. These represented additional measures to streamline the evolving program.

The FY 1989 program announcement (*15*) was the last NCPS issued. For FY 1990, CDC issued only a "Guidance on Continuation Funding" to existing recipients and neither accepted any new applications nor prescribed any fundamental changes from the previous year.

Conclusion

CDC programs in the States to prevent HIV-AIDS began in 1985 and were created in an unconventional fashion, initially because of the need to quickly respond to the public health emergency. Appropriations of funds for CDC programs predated by several years any specific legislation authorizing them, which afforded uncommon flexibility to the evolving CDC response to the epidemic during those years. The rapidly moving nature of the HIV-AIDS epidemic, particularly in its scientific and epidemiologic aspects, demanded a continuation of this pragmatic approach. The prolonged period of rapid change combined with a positive response to those changes by the CDC programs probably best explains why the approach was endorsed for so long by decision-making levels within the Federal Government.

As they prepare to carry out HIV-AIDS prevention activities under the specific authorization of

the CARE Act, for example, State programs are once again evolving. This time the evolution is from a solid base of operations established over several eventful years. The addition of early intervention services under the CARE Act is a milestone. This service component supplements previously developed educational and outreach initiatives by meeting both a genuine human need and a need to consolidate the many established efforts of State HIV prevention programs.

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