
Community-based Organizations and CDC as Partners in HIV Education and Prevention

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Synopsis

By 1982, community responses to the acquired immunodeficiency syndrome (AIDS) epidemic were evident in some cities in the United States. Community responses were planned, developed, and coordinated largely by service-oriented, community-

based organizations. Indirect evidence suggests that such organizations' activities mainly were in the form of attempting to discourage behaviors associated with the transmission of human immunodeficiency virus.

During 1984, Centers for Disease Control (CDC) assessed the educational activities of community-based organizations and public health agencies in several cities nationwide. Investigators found that in those cities where health education had become a secondary activity within a health department, prevention activities tended to be ineffective. They noted that the challenge of the epidemic lay in finding effective strategies for disseminating relevant information. They concluded that prevention efforts directed to groups at risk needed to be appropriate to the lifestyle, language, and environment of a particular risk group. CDC recognized these findings by adopting a policy of support of community-based organizations in its overall AIDS prevention strategy.

IN 1989, the Centers for Disease Control (CDC) began a program of direct support of community-based organizations (CBOs) to assist HIV education and risk reduction activities in the 27 metropolitan areas most affected by the acquired immunodeficiency syndrome (AIDS) epidemic.

The program from its inception has been directed to organizations that are working with members of racial and ethnic minority groups and others at highest risk for infection with human immunodeficiency virus (HIV). Among the groups served are blacks, Hispanics, Native Americans, Asians, Pacific Islanders, and Caribbean Americans. The special risk categories are youth, men who have sex with men, intravenous drug abusers, female sex partners of men at risk, prostitutes, and the homeless. Services are being provided in such settings as community centers, homeless shelters, drug treatment programs, churches, housing projects, correctional facilities, and on the street.

Direct funding to CBOs augments CDC's usual procedure of funding such activities indirectly through awards to State and local health departments. As with CDC's indirectly supported CBOs, directly funded organizations are expected to pro-

vide HIV prevention messages to high-risk groups and persons who are hard to reach through health agencies. Early evidence suggests that CBOs will meet this expectation.

Direct funding, mandated by Congress in 1988, significantly expanded CDC's existing efforts to implement a coherent health education and risk reduction strategy involving both State and local health departments and CBOs.

Early Years

As early as 1982, grassroot responses to AIDS materialized in several U.S. cities as service-oriented organizations began to develop strategies to prevent AIDS in their localities. The earliest AIDS service organizations represented homosexual male populations in major urban centers, as the disease affected primarily white, homosexual, and bisexual men at that time (1). The first AIDS service organizations emerged in New York and San Francisco, two cities that accounted for more than half of all the then reported cases of AIDS in the nation (1).

By 1982 both the Gay Men's Health Crisis in

New York City and the San Francisco AIDS Foundation had been established. Both provided services for persons with AIDS and support services for families and friends of persons with AIDS. Soon, both developed outreach programs for HIV education and risk reduction.

The effectiveness of the efforts of AIDS service organizations could not be externally validated because the organizations lacked any systematic approach to HIV education and risk reduction activities. However, indirect measures indicated that the community network was beginning to be successful in discouraging unsafe behaviors. In 1984, rates of reported rectal and pharyngeal gonorrhea among men 15 to 44 years of age in New York City declined to their lowest levels in 7 years (2). The decline coincided "with the period of heightened awareness and concern about the incidence of acquired immune deficiency syndrome (AIDS) among homosexual males" (2). A similar decline was noticed in other urban centers where AIDS service organizations were providing HIV-associated outreach activities and education. CDC interpreted the declines as indirect measurements of the effectiveness of HIV education and risk reduction interventions that were being delivered by community-based organizations serving that population.

In 1984, CDC assessed AIDS-related educational efforts in several high-incidence areas. CDC hoped to identify effective interventions and, by generalizing from the experience of AIDS service organizations, to develop a nationwide HIV education and risk reduction strategy that would lead to a decline in the incidence of AIDS by modifying HIV risk behaviors. The assessment would evidence CDC's commitment to the concept that culturally sensitive HIV education and risk reduction must be an integral part of the nationwide response to AIDS.

Nine Cities Study

In 1984, CDC selected nine cities for studies to assess HIV education and risk reduction programs: San Francisco, Los Angeles, New York, Miami, Newark, Chicago, Washington, Houston, and Atlanta. Eligible cities had to have reported at least 40 cases of AIDS, show that AIDS-related health education and risk reduction activities were being conducted, have at least one AIDS service organization providing HIV education and risk reduction activities, and allow investigators to examine the activities.

Teams of CDC personnel and consultants visited

cities and evaluated efforts by AIDS service organizations, public health agencies, and health care providers. The teams documented the number of government and nongovernment agencies involved, the activities of the organizations and agencies, and the goals and objectives of each program. Information was gathered about the group served, the program's direction, what educational materials were used and how they were developed, and the services delivery environment (clinic, health department, or bathhouse, for example) and the results were evaluated.

The final report (3) shows that researchers identified 73 organizations with AIDS-related activities. Of these, 59 involved HIV education and risk reduction activities. They were classified as public health organizations, AIDS service organizations, hospitals or clinics, and others such as coalitions, research centers, foundations, or institutes. Of the 59 involved in HIV education and risk reduction activities, 20 were AIDS service organizations. Their activities included hotlines, speakers bureaus, outreach to both intravenous drug abusers and homosexual and bisexual men, peer counseling, individual counseling, and volunteer training.

A significant finding of the study teams was that in most cities, collaboration between State and local health departments and AIDS service organizations had not materialized. The exceptions were New York and San Francisco. The report concluded, however, that the San Francisco Health Department's response was the only one that could be replicated. It included funding of CBOs to carry out risk-reduction activities, contracting with agencies to carry out services, and provisions for monitoring grantees.

One of the survey teams noted that in those cities where health education was a secondary responsibility within a health department, the programs tended not to be broad-based and to be ineffective. According to the team, the challenge of the AIDS epidemic lay in finding effective strategies for disseminating relevant information.

In a traditional sense, the team noted, the primary users of scientific information are scientists, for whom the transfer of knowledge occurs through journals or within highly structured conferences. In the case of AIDS, however, the primary users of the knowledge base are the AIDS service organizations that translate knowledge into programs to educate people about risk behaviors. As the team noted, often translation means using graphic language to provide explicit advice about sexual behaviors or needle sharing, and educating

means transferring information in nontraditional settings.

The team concluded that for HIV education and risk reduction activities to succeed within a special population, they must be appropriate for and responsive to the lifestyle, language, and environment of the members of that population. Successful efforts require the full collaboration of Federal, State, local health entities, and CBOs.

According to the team, Federal agencies involved in AIDS-related activities need to

- Support research activities that expand the knowledge base about AIDS so that program planners can make decisions about AIDS prevention educational programs;
- Refine and develop communications systems to ensure that research findings are disseminated to relevant agencies and organizations;
- Develop models and provide technical assistance and training to help program planners use data for their risk-reduction and educational program models; and
- Identify innovative AIDS health education programs and support the diffusion of innovations in other communities.

CBO Collaboration

Collaboration between government agencies and community-based organizations with access to a particular group at risk has been a traditional approach in public health in the United States. In writing about syphilis in "Shadow on the Land" in 1937, Dr. Thomas Parran, then Surgeon General of the Public Health Service, said "communities must take the initiative, must participate according to their ability in the effort to control their own syphilis" (4a). Federal and State health leaders, he argued, must offer concrete help to the communities. The hope for eradicating syphilis, he believed, lay in the fact that voluntary organizations "have included syphilis control as a major objective in their fight to improve all health status" (4b).

Except for the enduring commitment of the American Social Health Association, syphilis control never materialized as a focus of volunteerism, perhaps because of the disease's historic stigma and because it became readily treatable with the availability of penicillin in the 1940s. Conversely, volunteerism was a hallmark of the AIDS epidemic from the outset, thanks to the homosexual and bisexual community. CDC, knowing that communities were taking the initiative, wanted to assess and evaluate

what was being done. The aim was to investigate ways to help other localities control AIDS among their own populations.

In 1984, CDC responded to a request from the United States Conference of Mayors (USCM) to provide funds for an information interchange on AIDS. CDC funded the interchange so cities affected by the epidemic could share relevant information about the disease. The following year, CDC awarded USCM money for AIDS prevention activities, money that USCM, in turn, used to support AIDS prevention programs.

Funding USCM proved an effective way for CDC to support CBOs and extend prevention efforts to populations most affected by the epidemic. USCM represents about 860 cities; 90 percent of all AIDS cases reported to CDC are in areas under the influence of the conference. With CDC's support, USCM provides seed money to CBOs; the funding allows the CBOs representing affected populations or cities to gain valuable experience in HIV education and risk reduction efforts. USCM provides technical assistance to CBOs, recognizes successful programs, and provides them a national forum to allow replication of their efforts.

CDC's strategy for HIV prevention was to develop a comprehensive HIV education and risk reduction program. CDC developed AIDS community demonstration projects and projects to test innovative risk-reduction approaches. Later came AIDS prevention through cooperative agreements made directly with minority group CBOs. However, both of these followed the support of CBOs through the HIV education and risk reduction cooperative agreements with the States. This program now supports approximately 300 CBOs.

The tenor of CDC's HIV prevention plan was established in two program announcements (5, 6). Their purpose was to support ongoing HIV prevention efforts, to discover innovative interventions, and to generalize from the experience of existing programs so that successful interventions could be transferred to other localities.

The availability of funds for community-based demonstration projects and innovative projects for AIDS prevention activities was announced in 1985. CDC wanted to forge collaboration between public health entities and CBOs "serving the interests of groups at risk for AIDS" and to support development of interventions that, if effective, could be used by other programs. Only public health entities were eligible to apply for the community-based projects. A range of organizations was eligible for

the innovative projects, however, such as public health entities and other public or nonprofit private community organizations, educational institutions, or organizations that could "demonstrate the capacity to work in close cooperation with State or local health departments on the prevention and control of AIDS."

The announcement included as an evaluation criterion, both for the community-based and the innovative projects, "Evidence of the ability of the applicant to generate community cooperation and support for AIDS prevention activities and maintain close collaboration and working relationships with CBOs serving the interests of groups at risk for AIDS." All subsequent announcements stipulated collaboration and cooperation between public health entities and CBOs.

In addition to the desired collaboration outcome, CDC hoped that theory-based interventions could be developed. If so, prevention strategies could be transferred to other localities, increasing the efficiency of efforts. Realizing this goal, however, depended on mutual trust and the respect of the various entities working together. CDC sought to achieve cooperation among entities by requiring recipients to "provide learning opportunities for other State and local personnel that are planning, implementing, or evaluating AIDS health education/risk reduction programs." The innovative project directed the recipient to "participate in technology transfer to personnel from other State and local communities."

CDC's hope for transferability was shown in the 1986 announcement. It contained the same language for collaboration with CBOs, but, in the section detailing cooperative activities, required the recipient to remain flexible enough to respond on short notice to CDC requests to test new strategies, "to duplicate or examine the relevance of potentially important program findings from AIDS innovative Risk Reduction cooperative agreement recipients, program areas, or other Community-Based Demonstration Sites."

Minority Group Initiatives

In 1985 and 1986, the majority of AIDS service organizations and CBOs with an AIDS-specific focus had evolved in homosexual and bisexual communities in urban settings where the epidemic was most evident. The epidemiology of the disease directed prevention efforts, as illustrated by the funding pattern for the innovative project announced in July 1985. Of eight projects funded,

four focused exclusively on homosexual and bisexual males. Two addressed intravenous drug abusers, one addressed the issue of homophobia among physicians, and one was directed to black and Hispanic youth.

By 1986, however, the race, age, and sex distributions of persons with AIDS, which had remained relatively stable since 1981, were revealing a disturbing trend. Blacks and Hispanics were being disproportionately affected by the epidemic (7). Nonetheless, many in these populations tended to see AIDS as a disease of white homosexuals and not as a disease affecting their communities. Such denial was common, fueled in part by the media depiction of AIDS as "The Gay Plague."

In March 1987, CDC announced the availability of funds to assist States and local health departments in maintaining HIV education and risk reduction activities (8). CDC required recipients to direct these activities "to black and Hispanic populations and involve representatives of these populations in the overall effort to ensure a maximum level of awareness that they have been disproportionately affected by AIDS, particularly perinatal AIDS, and need to consider measures that will prevent the further spread of HIV."

In August 1987, CDC announced a supplemental appropriation of funds for activities related to minority populations (9). It made about \$7 million available to State and local health agencies that had been awarded cooperative agreements previously. The purpose was to expand initiatives directed to minorities for helping to prevent the spread of HIV. The program announcement said, "Where it is reasonable and feasible . . . it is clearly preferred that the major thrust of the educational service delivery effort be accomplished by funding minority community groups and AIDS service organizations."

The plans to announce supplemental funds were discussed at a national minority conference held in Atlanta, GA, in 1987. However, many of the more than a thousand participants were displeased that State governments were chosen to receive and further disburse the funds. The conference revealed a clear understanding that the lack of a broadly based, prior working relationship with State HIV prevention programs had fostered misgivings. Some preferred CDC to fund local minority organizations directly. The demand for local or community control was already significant and growing.

Forty-one programs applied for and received funding on September 28, 1987. The 18 programs not applying believed that funding provided

through the initial award announced in March was sufficient to address the minority AIDS problem within their jurisdictions.

Of the \$7.4 million awarded for special minority initiatives, almost \$5.6 million was to be used for contracting with CBOs representing or serving minority populations through 39 programs. After these funds were made available, State HIV prevention programs initiated a competitive award process to distribute them.

The FY 1988 program announcement (10) included the strongest wording to date regarding funding of minority-focused CBOs. The section on cooperative activities prefaced the required recipient activities with this note: "The following activities should be planned and conducted in collaboration and coordination with local health departments and with the participation of AIDS service organizations; community groups/organizations, especially those with a minority membership and focus. . . ." The section concluded with, "Evidence of collaboration, such as AIDS prevention plans submitted by local health departments in major metropolitan areas, AIDS service associations, minority groups, and service delivery programs, should be included."

The cooperative activities section included a separate category entitled "Reaching Minorities at Risk." It required recipients to develop systematic efforts in minority communities to build their capacity to provide HIV prevention education and to consult with the leaders and representatives of minority populations to develop strategies jointly. Another requirement was to provide direct financial assistance to CBOs responding to the needs of minority populations and to provide them technical assistance on a variety of issues ranging from program planning to grant writing. (The 1988 Minority Conference addressed this CBO need by including on the agenda a workshop on grant writing.)

During the time between the February program announcement and the 1988 conference on AIDS in minority populations, CDC negotiated with the States to set aside money to fund minority organizations for HIV prevention. More than \$12 million of cooperative agreement funds were restricted and dedicated to minority outreach and HIV prevention. The highest amount restricted was \$1.5 million, and the lowest was about \$13,500. However, few CBOs had an accurate perception of the costs involved in implementing prevention programs. Therefore, the awards from States to the CBOs were generally small, with many falling between

\$2,500 to \$10,000. Furthermore, State and local regulations and administrative procedures produced delays in the award of funding to CBOs in several areas.

Frustrated by such delays and by the enormity of HIV disease within their own communities, representatives of minority CBOs registered complaints with their elected officials at various levels. The officials perceived that CDC could provide quicker funding to CBOs if it did so directly. As a result, a mandate for CDC to fund CBOs directly was written into the appropriations bill for AIDS prevention activities for FY 1989.

Direct funding, however, raised some important questions. For instance, how would CDC allocate resources among thousands of potentially eligible CBOs? Another important question addressed how independently funded CBOs would interact with the State HIV and AIDS program, since CDC expected the State program to provide the leadership. How to coordinate an effort that avoided wasteful duplication or competing or contradictory educational messages was a concern. The appropriations language limited the eligible applicants to those in metropolitan areas having the highest number of AIDS cases. The restriction helped to resolve the problem of how to allocate resources. Direct funding became more feasible even though the potential number of applicants still exceeded 6,000 organizations. Other concerns could be addressed only after the award process was completed.

The program announcement for Cooperative Agreements for Minority and Other Community-Based Human Immunodeficiency Virus (HIV) Prevention Projects appeared in the Federal Register on January 9, 1989 (11). Eligible applicants were nonprofit CBOs in the metropolitan statistical areas (MSAs) most affected by AIDS. The program announcement said that about \$5 million would be awarded to CBOs that "represent and serve minority persons and whose governing body is composed of more than 50 percent racial and/or ethnic minority group members (Asians, blacks, Latinos/Hispanics, Native Americans, and Pacific Islanders)." CDC gave priority to at least one minority project in each eligible MSA. It planned to fund about 15 to 20 CBOs serving populations at risk for HIV infection regardless of their ethnic or racial demographics. As with all previous awards, the recipients were required to collaborate with State and local health departments.

In November 1989, CDC announced the availability of supplemental funds in 1990 (12). The

announcement extended eligibility to four additional MSAs "where minority populations have been heavily affected by the HIV epidemic."

CDC conducted a series of workshops to assist representatives of CBOs from the MSAs in developing their applications. The workshops consisted of 1-day preapplication technical assistance sessions. They familiarized leaders of CBOs with procedures for applying for Federal funds for HIV prevention and reviewed the types of programs and activities that could be supported with Federal money. Beginning in January 1989, 23 workshops were conducted, with more than a thousand representatives attending. CDC received 373 grant applications.

All applications went through an exacting review process beginning with a review by four panels made up of AIDS-knowledgeable people, mostly outside CDC. One hundred applications were recommended for a second level of review, again by non-CDC panelists. The process recommended 64 organizations and CDC awarded about \$11 million to all 64 in 1989.

(Because the November 1989 announcement had added four additional MSAs to the eligibility list, CDC conducted additional workshops. These were completed in April 1990. Applications from these MSAs were reviewed, and in January 1990, CDC awarded funds to an additional four organizations.)

Six project officers for the CBO initiative were added to the Division of STD/HIV Prevention by February 1989. They reviewed grant applications and negotiated with successful applicants between July and September 1989. Since few of the CBOs had any prior experience with government grants or cost-reimbursement contracts, the Inspector General of the Department of Health and Human Services audited the financial management capabilities of all potential grantees. The audits revealed numerous deficiencies, primarily inadequacies relating to time and attendance records, policies for use of consultants or for procurement, inventories of property or equipment, separation of duties, and accounting systems. Four of the CBOs with whom negotiations were conducted failed to pass the audit and were not funded. Funding restrictions were placed on most of the others until corrections or improvements were made.

The audit process consumed considerable time. Consequently, many of the CBO projects lost about half a year of activity. Most are now fully operational and are more solidly structured organizations.

Conclusion

Both State-funded and directly funded CBO programs have taken HIV prevention into nontraditional settings, such as city streets and correctional institutions. Many of them employ persons identified with such subject populations as prostitutes, addicts, and teenagers. Different settings encourage a variety of nontraditional activities. Recovering addicts work as street outreach educators trying to get users into treatment or to get them to stop using or sharing drug injection equipment. In other projects, rap music is the vehicle for delivering AIDS education to black youth. Teenage peers provide education on the proper use of condoms to a mixed group of teenagers. Other funded CBOs use group sessions to promote safer sexual behaviors among homosexual and bisexual minority group men.

Since it first began making funds available to public health agencies and to CBOs or AIDS service organizations, CDC had hoped to forge a collaborative effort in developing a nationwide HIV prevention effort. CDC believed that, through its support, innovative preventive strategies would emerge that could be shared by others. Many of the strategies evolving through the directly funded CBO initiative are proving to be innovative, but their effectiveness and their applicability elsewhere have yet to be evaluated systematically. CDC has made the evaluation of the activities of the organizations a high priority. Evaluation is a key component of the technical assistance CDC provides CBOs.

Epidemiologic data indicate that blacks and Hispanics in particular are disproportionately affected by HIV and AIDS. These data evidence the urgency of sustained prevention efforts directed toward them and other minority and ethnic populations. CDC's commitment to collaboration with local communities and with CBOs representing specific populations is demonstrated by its prevention efforts in the 1980s.

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Evaluating the CDC Program for HIV Counseling and Testing

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A version of this paper was presented at the Assessing AIDS Prevention International Conference, Montreux, Switzerland, October 29-November 1, 1990, and at the World Health Organization's Global Programme on AIDS, Consultation on the Assessment of Counselling Efficacy in HIV/AIDS, Geneva, Switzerland, November 13-16, 1990.

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Synopsis

The Centers for Disease Control is conducting two investigations of the outcomes of HIV counseling and testing services offered persons at high risk for infection with the human immunodeficiency virus (HIV). One investigation is a trial conducted

at sexually transmitted disease clinics where an enhanced version of HIV counseling and testing is compared with a standard version. The other investigation is a longitudinal study of the effects of HIV counseling and testing in drug treatment programs that use methadone therapy.

In the evaluation, comparisons are being made of different ways of offering HIV counseling and testing and of the effectiveness of the program among persons who know their HIV serostatus and those who do not. The outcome variables include self-reported sexual and drug-using behaviors, together with corroborating laboratory tests, drug treatment compliance, mental health effects, and services utilization. Methodological, practical, and sociopolitical challenges were encountered in the evaluations. Possible solutions to the problems are described.

The authors conclude that the designs of the evaluations were appropriate, but that considerable resources are required to carry them out. In settings with low levels of resources, thorough evaluation of the process and an assessment of the immediate outcomes may be the most appropriate evaluation strategy. As HIV counseling and testing are of fundamental importance to national and international HIV prevention efforts, their evaluation is a critical issue.

THE ENZYME-LINKED IMMUNOSORBENT ASSAY (ELISA), which detects antibodies to the human

immunodeficiency virus (HIV), was licensed in 1985 and first used in screening the blood supply,