
NAN—A National Voice for Community-Based Services to Persons with AIDS

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Synopsis

Because of the variety of needs engendered by AIDS, a broadbased response to the epidemic is warranted. The traditional medical model, with its emphasis on inpatient hospital care, is expensive and fails to address other needs of people with AIDS (PWAs). This paper outlines an alternative

model: the community-based response, or continuum-of-care model. It builds on earlier community models of an integrated network of service providers who can better meet a range of needs of PWAs outside the hospital. Although the model may include a designated hospital AIDS unit that supplies inpatient services, the continuum-of-care model incorporates other nonacute and psychosocial services offered through community-based providers, and these services rely to a large extent on volunteers.

Nationwide, more than 400 community-based AIDS service organizations have been formed in response to the growing AIDS epidemic, or have evolved from existing organizations. The National AIDS Network (NAN) was formed in 1985 by five such organizations to represent at the national level the vision of community-based AIDS care. As the nexus for a national community-based response, NAN acts as a conduit for service providers to share experience as well as a clearinghouse for information and programs.

PEOPLE WITH AIDS (PWAs) GENERALLY ARE treated according to a traditional medical model: after inpatient treatment in an acute care hospital they are released into the community following hospital-based discharge planning that involves little or no social services support. Because of the reliance on inpatient services, total care and treatment costs are high. This model tends to view AIDS as strictly a medical, rather than a community problem.

There is an alternative—networks to deliver services that are based in the community and address bottom-line costs. Their existence is also a recognition that nonacute medical and psychosocial services for PWAs generally are delivered more effectively in the community.

The continuum-of-care model considers AIDS a community problem. Hospital care is but one component of an integrated network of community-based medical and psychosocial support services. These resources can include outpatient clinics, home health care, hospices, practical support services, housing, financial planning, and related other services. The success of this model

depends upon the linkage of all these key components.

San Francisco's continuum-of-care model, unique because of the city's demographics and culture, includes a designated inpatient hospital AIDS unit (San Francisco General Hospital), a hospital-based AIDS outpatient clinic, and a comprehensive, integrated network of home and community-based service providers.

Advantages of the Community Model

The Public Health Service's Centers for Disease Control in 1985 forecast an average lifetime total cost per AIDS patient of \$147,000 based on 167 inpatient days over the patient's lifetime (1). Subsequent forecasts, however, reflect considerably lower costs and reduced hospital stays. For example one report on medical costs for AIDS in San Francisco estimated a lifetime per patient total of only \$27,571 based on 34.7 total in-hospital days (2).

A 1986 report on the costs of treating AIDS in San Francisco noted that hospitalization accounts

for 80 to 90 percent of the total costs of treating AIDS. It noted further that San Francisco's community-based service network "is an important factor in the reduced length of stay and expense of hospitalizations for persons with AIDS in San Francisco" (3).

As demonstrated in San Francisco, the continuum-of-care model offers both better quality and more cost-effective care for PWAs than the medical model. Recent studies reflect the effective development of a community-wide, diversified response to AIDS in San Francisco, noting that the cost of treating AIDS is significantly lower, and the quality of life for PWAs higher, when substantial amounts of services are provided outside the hospital through networks of medical care and psychosocial services that are heavily staffed by volunteers (4). Scitovsky and co-workers similarly observe that "costs of treating patients with AIDS can be reduced substantially given community support services that help to keep patients out of the hospital so far as medically possible" (2).

Other cities could adapt the San Francisco model to their circumstances; its key components are these: (a) a committed local government, (b) local funding resources, (c) a strong base of community service agencies that rely on a pool of volunteers, and (d) a sociopolitical environment in which people are willing to view AIDS as a community problem and fund a comprehensive, integrated program.

Although San Francisco has all the key components in place, community-based providers are struggling to fill enormous gaps in local resources, especially in chronic care, skilled nursing care, and outpatient medical care for PWAs. Many smaller communities, with fewer resources to deliver social and medical services (visiting nurses associations, hospices, home health care agencies, and so forth), are poorly equipped to meet the needs of PWAs. Such agencies cannot serve as an anchor for a community-wide network that integrates community-based medical care and psychosocial support services. There is a critical shortage of skilled nursing care beds in every city, and few nursing homes are willing to take PWAs. The feasibility of providing home medical care typically depends upon the resources of a local hospital. As of June 1987, 13 States had no hospital-based home care programs that were caring for PWAs, and 11 States had only one such program. Most home care programs are in major cities and are operated through large hospitals that already have large numbers of PWAs.

Despite the promise evidenced in the continuum-of-care model, important gaps in services are forecast for the future, largely because the demographics of AIDS are changing. Although the highest cumulative numbers of AIDS cases to date have been reported in New York, California, Florida, Texas, New Jersey, Illinois, Pennsylvania, Massachusetts, Georgia, and the District of Columbia, AIDS is becoming increasingly a suburban and rural disease, especially as many PWAs return from their adopted urban homes to their small hometown communities.

The Public Health Service expects that by 1991, 80 percent of all AIDS cases will occur in areas outside New York City and San Francisco. This trend has begun already: Houston, which reported 176 AIDS cases in 1984, had accumulated 1,347 cases as of August 1987. Dallas, with 84 cases in 1984, had accumulated 784 by August 1987. Denver, with 37 cases in 1984, had 353. And Seattle, with 52 cases in 1984, had 395.

To minimize the gaps in the provision of services in second tier incidence areas, we must begin planning now. Leaders in both private and public sectors must recognize their responsibility to provide services during the AIDS epidemic. The key ingredient is community-wide cooperation. All segments of society must be galvanized to respond effectively to the hundreds of thousands of people who will be diagnosed with and die of human immunodeficiency virus-related infections.

The National AIDS Network Emerges

Private sector organizations were formed early in the AIDS epidemic to provide community-based care to PWAs. In 1982 New York City's Gay Men's Health Crisis became the first. Since its founding, other community-based organizations across the country have been formed to deliver and coordinate the variety of services PWAs need. These community-based organizations are manning the front lines in the fight against AIDS.

Community-based AIDS service providers soon recognized their need to network and interact with one another and to have an institutional forum for comparing notes and sharing information. The National AIDS Network (NAN) was created by five pioneering community-based organizations—Gay Men's Health Crisis, AIDS Project Los Angeles, San Francisco AIDS Foundation, Baltimore's Health Education & Resource Organization, and Boston's AIDS Action Committee—as a networking and resources center of the commu-

nity organizations that had arisen to meet the challenges of the proliferating AIDS epidemic. NAN allows the community service providers to interact, provides them with tools to do their jobs effectively (such as model programs and information on experimental drug protocols) while it facilitates partnerships with established public health and professional organizations. NAN represents at the national level the community model of AIDS service provision.

Providers of services and education at the community level can easily get caught up in the epidemic's shifting tides. NAN lends a certain continuity to community-based AIDS services, and it serves as the focal point of what might otherwise be disparate efforts nationwide. The agency acts as a conduit for the accumulated experience and shared wisdom in the still-new war on AIDS. NAN is able to bring the expertise and proven methods of older community organizations to bear on the questions and obstacles facing new organizations in smaller cities with a low incidence of AIDS.

NAN serves a diverse constituency. Some of its more than 400 member agencies were formed specifically to respond to the AIDS crisis, and others grew out of existing social service agencies, gay community health clinics, hospitals, or health departments. Some are in large cities with heavy caseloads and supportive community leaders. Others are in small towns, and their staffs work under hostile circumstances. Some work with children; others with adults. Some provide housing; others provide support groups and counseling. Some operate crisis intervention hotlines; others operate information and referral hotlines.

Grassroots organizations have sprung up all over the country—more than 400 as of January 1988—to meet the varied needs that AIDS has engendered. Most models for effective AIDS services were developed initially by the staff of community-based organizations who adapted concepts from existing organizations that deal with other diseases and populations. "Buddy" programs, home health care, and group housing were adapted to the needs of PWAs and the community organizations serving them. AIDS education, also, with the kind of sensitivity to cultural, ethnic, religious, and sexual realities recommended in the National Academy of Sciences' 1986 report, "Confronting AIDS," has been generated most effectively by community-based organizations (5).

Local organizations are NAN's strength. For example, the ability of the AIDS Action Committee (AAC) of Boston to form partnerships with

public health officers and build alliances with elected officials in the State generated more than \$1.3 million in State government funding in 1987 alone. The AAC serves more than 450 persons with AIDS. The agency's leaders have worked with Massachusetts Governor Michael Dukakis and Boston Mayor Raymond Flynn to facilitate education programs and to minimize public hysteria.

Boston has many of the necessary components of an effective community-based model of care, but it still is short of resources. Yet some of NAN's other constituents are facing an even bleaker picture—Houston, for example. Although Houston ranks fourth in AIDS cases nationally, and the AIDS Foundation Houston (AFH) serves nearly as many PWAs as Boston's AIDS Action Committee, AFH has received a mere \$6,000 in government funding. Its staff of 2 have the herculean task of providing services to some 425 clients. The commitment of these two is humbling. Like Dr. Rieux in Camus' too-relevant novel, "The Plague," AFH staff say they do their work because they *have* to do it; if they did not take care of these people, no one would.

NAN staff have visited most agencies in our network to identify gaps in their services, to keynote their conferences, and to help them locate new funding resources. Staff also meet regularly with officials of Federal agencies, other national organizations, the media, foundations, and corporations to discuss AIDS and the community response to it.

As the networking organ of this body of 400-plus diverse organizations, one way that NAN facilitates partnerships among service providers, as well as with other public and private organizations responding to AIDS, is by holding conferences. In October 1987, for example, NAN sponsored a planning conference—"AIDS Into the Nineties"—in conjunction with the American Medical Association (AMA), the Association of State and Territorial Health Officials, and the Centers for Disease Control (CDC). This conference brought together 150 persons from the whole range of institutions responding to AIDS to chart some of the major gaps in the current response to the epidemic.

NAN participates in an extended coalition to represent service providers around the United States and to ensure that their voices are heard at the national level. As the nexus of the community-based response, NAN has facilitated partnerships among key elements of American society, including government agencies, health and research organizations, representatives of the gay and lesbian

community, minority communities, the media, charitable foundations, and private enterprise. NAN works with the AMA, National Leadership Coalition on AIDS, National Association of People with AIDS, National Minority AIDS Council, National Urban League, YWCA, and CDC, among others.

NAN's challenge is to nurture the diversity of its constituency while simultaneously fostering a national unity—to unite under one banner the community organizations and people battling AIDS. To meet the challenge, NAN maintains four programs to serve its members.

NAN's Programs

Clearinghouse and resource development. NAN's objective is to assist members in acquiring the technical ability necessary to meet their responsibilities. This empowerment involves making current resources and model programs accessible to community service providers. NAN's Clearinghouse and Resource Development Program has one of the nation's most comprehensive archives on the AIDS epidemic and the community response to it. Knowing where to find information and referring inquirers to the right sources are major functions of the clearinghouse.

The clearinghouse serves as the agency's library and news morgue. It maintains more than 35 different subject files of news clips about AIDS from small and large circulation publications. The clearinghouse regularly receives new AIDS-related books, videos, and brochures, and subscribes to the magazines, national newspapers, journals, newsletters, and reports considered essential to being current on AIDS issues. It houses a broad collection of educational literature and uses sophisticated database information storage and retrieval programs to assist members as they search for models for their own education programs.

NAN publishes the "NAN Directory of AIDS Education and Service Organizations," the only comprehensive listing of AIDS service providers. The Directory is updated quarterly; it lists more than 400 community-based AIDS service organizations, as well as key Federal, State, and local public health agency officials.

As part of NAN's resource development, we also produce technical assistance packets. These explore in depth a specific topic of special interest to NAN's members and their clients. Recent topics have included "2176 waivers" for State-provided Medicaid, media relations, and "buddy" program

development. NAN also supplies resource directories, manuals, and guides; many of these have been developed by larger, more established AIDS service providers. These resources are essential tools, particularly for incipient, smaller organizations.

Minority affairs program. The difficulties of providing education and services to minority communities became apparent to NAN's staff early on. A report NAN produced in early 1987, "AIDS Education and Support Services to Minorities," quantified the lack of services and prevention for minority ethnic groups (6). To meet the unique challenges of reaching these populations, NAN created the Minority Affairs Program. This 15-month-old effort has been recognized by national minority institutions in the black, Latino, Asian, and Native American communities. In 1987 the Minority Affairs Program was asked by the Public Health Service's Office of Minority Health to help bring together key national minority leaders in two forums, one in Crystal City, VA., the other in Atlanta, GA.

The minority program was created specifically to enable NAN members to exercise good and informed leadership on the prevention, education, and service needs of minority gay and bisexual men, intravenous drug users, women, and children. The Minority Affairs Program pursues its mission by (a) ensuring that NAN's minority constituents receive the full range of services provided by all NAN programs; (b) ensuring that they get programs and services that respond to their specific funding, administrative, organizational, and skill-building needs; (c) ensuring that NAN's nonminority constituents get services that enable them to address minority issues more effectively; and (d) present issues of concern to minorities to organizations on a national, regional, and local level.

The program provides several services. NAN Multi-Cultural Notes, a monthly newsletter on issues of concern to minority communities in the fight against AIDS, helps to connect the growing network of AIDS services directed toward the black and Hispanic communities. The program staff also conduct workshops—"technical assistance weekends"—which bring together a group of experts for working sessions on a given topic. One workshop, for instance, focused on education outreach programs directed to IV drug-using popu-

lations and brought together some of the country's leading authorities on issues concerning IV drug users. These workshops serve as the basis for the program's own technical assistance packets. In addition, the staff pursue a vigorous schedule of speaking engagements.

Communications/media relations program. As an information-gathering and disseminating agency, communications and media relations are integral to NAN's mission. Three regular publications, numerous periodic resource directories, and technical assistance packets serve a variety of constituent needs. A proactive media relations program puts forward the interests of community-based AIDS service providers and the vision that guides them.

The Communications/Media Relations Program has joined the American Foundation for AIDS Research (AmFAR) in a national AIDS education campaign using donated advertising space provided by the Ad Council. In 1987, the program sponsored the first "Americans Who Care" awards ceremony at the French Embassy. AIDS service volunteers from around the country were honored for their outstanding service and featured in an "Americans Who Care" book that NAN produced (7).

To facilitate communication among agencies, NAN actively solicits articles and input from members. The Communications/Media Relations Program works with an editorial sounding board to test ideas for stories and articles, garner new ideas and, above all, to ensure that NAN's publications and representation in the media reflect the most current, credible information available.

NAN's twice-monthly newsletter, *Network News*, provides news of concern to members and puts special emphasis on information of pragmatic relevance to community-based organizations. One recent issue, for example, included practical advice on coalition building from an AIDS organization in one State that can easily be applied to organizations in other States. The communications program produces NAN Multi-Cultural Notes, as mentioned previously. Finally, the NAN Monitor is a quarterly journal of feature articles and resources pertinent to the broad range of issues relevant to the community-based response to AIDS. The Monitor has the widest circulation of NAN's publications, reaching more than 3,000 individuals and organizations.

Field resources program. NAN's efforts at helping to empower AIDS service providers include sponsoring skill-building and networking conferences

and person-to-person working sessions. Field resources staff conduct site visits across the country. A grant from the Scott Paper Foundation allowed NAN to expand this program to employ a trainer who works with individual cities to identify gaps and provide consultants to assist their efforts.

In 1986, for example, NAN initiated a series of regional Counterpart Conferences designed to build skills and establish partnerships with local AIDS service providers. While the Minority Affairs Program's technical assistance weekend workshops bring together people from around the country to focus on a particular topic, the field service's workshops bring together service providers in a given region, encouraging networking and fostering an atmosphere of comradery. In 1987, NAN also sponsored two conferences, in New York and San Francisco, that explored direct mail fundraising for AIDS service organizations. In October 1988, NAN will host a "nuts and bolts" conference for service providers that will explore practical aspects of running a community-based agency: management, financial tools, information systems, fundraising, and case management.

NAN also supplies technical assistance via telephone consultation and 2-day intensive training workshops. In 1987 these were held in Nashville, TN, Springfield, MO., Houston, TX, St. Louis, MO, Topeka, KS, and Cleveland, OH.

NAN in the Future

NAN was established to provide direct services to, and be the voice of, community-based AIDS service and education providers—organizations that have responded with compassion and sensitivity to the impact of AIDS on the lives of people in their cities and regions. These organizations demonstrate what is finest in the human spirit and what is best about America—communities helping their own people and the growth of volunteerism that has been emphasized under the Reagan Administration.

The cornerstone of NAN is the empowerment of AIDS service providers in their communities; NAN seeks to provide opportunities for them to use their local resources to solve their own problems. As an organization with a national constituency, NAN recognizes that, although the strains of the AIDS epidemic on communities across the country are the same—testing the health and social service system, indeed the very fabric of our society—each

community is unique and must respond appropriately to its circumstances.

The people working to meet the challenges of the AIDS crisis can be overwhelmed by the work and the pain. They need a nerve center, a command post in the battle, as a base of mutual support and a clearinghouse for the latest resources and information. Likewise, they need to be united by a single vision—community-based, compassionate AIDS service provision. The National AIDS Network looks forward to serving those on the front lines and arming them for the continuing war on AIDS.

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“One sexual encounter can be all it takes to spread the AIDS virus from one person to another. We must know how to protect ourselves and our families.”

**– Jolene Connor
Nurse Counselor
Harlem, NY**



Call the AIDS Information line, 1-800-342-AIDS.

An Important Message from the U.S. Public Health Service
Centers for Disease Control