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AIDS Initiatives in Massachusetts: Building a Continuum of Care

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The Health Resource Office was officially established within the Massachusetts Department of Public Health in August 1985 to coordinate policy, education, research, and service response to the AIDS epidemic, and to focus attention on the social and economic impact of the disease. The actual work of the office was begun earlier, in October 1983. This article reviews the activities of the Health Resource Office from October 1983 through June 1987 in allocating resources for AIDS and ARC programs and services. It then describes the conceptual model that evolved during this period for the continuum of services needed to reduce HIV transmission and to provide services to those who are infected and ill.

In October 1983, the Massachusetts Governor’s Task Force on AIDS, appointed by Governor Dukakis, held its first meeting. At that time, there were 33 known cases of AIDS in the state. By December 1987, 1,174 cases had been reported in Massachusetts. The Task Force was comprised of individuals from the sectors of medicine, clinical research, epidemiology, public health, state and local government, and the legislature. Meeting on a monthly basis, it worked under the governor’s mandate to guide the state’s education, policy, and service response to the AIDS epidemic.

The Health Resource Office was formally established in the Massachusetts Department of Public Health (DPH) in the summer of 1985 to define public policy regarding the AIDS epidemic and to guide response to the myriad of health, social, and economic concerns it had raised. The Health Resource Office worked with the AIDS task force to ensure that policies developed to guide social interaction with those infected with human immunodeficiency virus (HIV) were based on medical and scientific evidence, not on fear and ignorance. The office has also been responsible for administering a program of research support; conducting extensive education and in-service training programs through its staff of health educators and through funding support provided to the AIDS Action Com-

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mittee of Massachusetts; and allocating resources for needed health and social services. Case surveillance and the state-sponsored anonymous HIV testing and counseling programs have been administered separately, through the Department of Public Health’s State Laboratory Institute. As well, a ten-bed inpatient AIDS unit has been established at the DPH’s Lemuel Shattuck Hospital by DPH staff at that facility.

Four goals were endorsed by the AIDS task force in June 1986 and were used by the Health Resource Office to guide resource allocation activities. These goals were as follows:

- to continue to support research in an effort to find a cure and an effective treatment
- to increase the availability of direct services to people with AIDS
- to further pursue reduction of the spread of HIV through education and outreach
- to maintain the state’s commitment to providing the leadership and guidance necessary to ensure care and compassion for those who are stricken with this illness

Massachusetts AIDS Research Program

In Massachusetts, state funds for efforts to deal with AIDS first became available in the beginning of the 1985 fiscal year, which ran from July 1, 1984, through June 30, 1985. Concern about the safety of the blood supply resulted in a $1.5 million appropriation by the Massachusetts legislature to support research into the cause, prevention, surveillance, methods of treatment, and cure of AIDS in order to protect the public health. (The antibody test to screen the blood supply for exposure to HIV was not available until the middle of that fiscal year, and was not approved for actual use by the Federal Drug Administration until April 1985.) Lacking an administrative precedent within the state purchase-of-service contracting rules for supporting research, the Health Resource Office devised a mechanism to award research funds via a Request for Proposal (RFP) process. The Massachusetts AIDS Research Council was convened by Bailus Walker, Jr., then commissioner of the Massachusetts Department of Public Health and chairman of the AIDS task force, to make recommendations for funding on the basis of a peer review of submitted applications. Although the Massachusetts Governor’s Task Force on AIDS included some of the nation’s leading experts on AIDS research, it was deemed necessary to convene a distinct body to allocate research funds in order to avoid conflicts of interest if task force members applied for support.

The Request for Proposal identified two categories of funding support: (1) pathogenesis and treatment of AIDS, and (2) epidemiological, social, and behavioral factors associated with AIDS.

The first category was intended to provide support for laboratory or clinical investigations, or both, into the basic science of the disease, including its cause; mechanism of infectivity and relationship to other illnesses; mode of transmission in the blood supply and methods to assure its protection; and other avenues of investigation with potential for increasing knowledge of the disease, preventing its further spread, and treating or curing those already infected.
The second funding support category was intended to identify (1) social and behavioral precursors to the disease and methods of intervention to prevent its continued spread, and (2) new approaches to the management of patients with AIDS and those infected with the virus.

Twenty proposals were funded in FY'85. Prior to the start of FY'86 and FY'87, the progress of funded projects was reviewed by the Massachusetts AIDS Research Council and recommendations were made for continued support on the basis of (1) an assessment of the progress that had been made during the previous contract period, and (2) the proposed activities to be pursued during the next funding cycle. By FY'87, eleven of the original projects were still being supported. Contracts to continue the eleven projects were renewed for the first six months of FY’88 (through December 1987) without review by the research council.

Ongoing administrative concern with justifying state support of AIDS research has centered on the need to find the appropriate focus for state funds in this ever changing arena. In order to ensure that state AIDS research priorities are appropriate and are not duplicative of national or other state efforts, an inventory of new funding sources (primarily federal funds) acquired by state-funded AIDS researchers since the award in FY’85 of the initial Massachusetts research support was identified as a priority in FY’87 for the following fiscal year. As well, identifying new areas for research was considered an appropriate focus for state efforts. These concerns were scheduled for consideration during the latter part of FY’88. Also, it was anticipated at that time that a new Request for Proposal would affect FY’89 AIDS research allocations.

Community Resources and Services

In June 1986, the Massachusetts Governor’s Task Force on AIDS endorsed the “Massachusetts Department of Public Health FY’87 AIDS Resource Allocation Plan.” Its purpose was to establish priorities for directing resource allocation efforts. Development of the plan was the result of information about community service needs which had been obtained by the Health Resource Office from a variety of sources.

In response to complaints and anecdotal information from providers, patients, and advocates about barriers to home care services experienced by people with AIDS, the Health Resource Office, during the fall of 1985, had conducted an informal assessment of physicians, hospital discharge planners, visiting nurses, and home health providers in an attempt to pinpoint the underlying reason(s) impeding access to service for this group. The information that was sought ranged from estimates of the number of people with AIDS who had been referred for service and of the actual number served to an assessment of how the home care needs of patients with AIDS differ from those of patients with other infectious or chronic diseases. Information was also sought regarding increased need for staff training and supervision, as well as reimbursement barriers to patient service.

In an effort to obtain more specific information on the service needs of individuals ill with AIDS or showing signs and symptoms of HIV infection, the position of community resource specialist was established in the Health Resource Office to document gaps in service for individual clients as a basis for targeting resources.

The first community resource specialist was hired in the winter of 1986 to work in the Boston area, where most of the state’s patients with AIDS live. Though an employee of the Department of Public Health, the community resource specialist was placed half-time...
at the AIDS Action Committee’s office in order to ensure her familiarity with client concerns and her availability for assisting AIDS Action Committee client service workers in their efforts to manage the most difficult-to-serve clients and obtain services for them. It was felt that because the community resource specialist was an employee of the Department of Public Health, some of the complexities of working through the bureaucracy might be reduced by capitalizing on personal relationships already established between staff in public agencies and by exerting an influence on administrative rules and procedures that might be found to hamper access to services. Three additional community resource specialists were hired by the end of FY’87 and were placed in targeted areas around the state, including Springfield, Worcester, and Barnstable County.

In addition to providing valuable information about the impediments experienced by patients with AIDS in their efforts to obtain access to entitlements and services, the community resource specialist is also in a position to document gaps in the availability of services as well as the need for new service entities within the spectrum of a comprehensive continuum of care. Information and inferences provided by the community resource specialist, in conjunction with those provided directly by the AIDS Action Committee and other sources, have been used as the basis for establishing priorities for resource allocation.

Expanding Home Care Services for AIDS Patients

With the need for expansion of home care services identified as a priority, a strategy for allocating resources to increase services and access to them was developed. An important principle guiding this program-development activity was that expanding the existing array of services that comprise the health care system (with modifications where necessary) to include services to AIDS patients was preferable to the creation of new service entities specifically for AIDS care. Under this principle, new services and program models would be developed when no other appropriate service existed. Following this principle would ensure that to the greatest extent possible, AIDS care would be financed through the current third-party reimbursement structure, leaving new resources available to fill gaps in the service spectrum. Clearly, the problems of access, that is, efforts to obtain services without insurance or with inadequate insurance coverage, would not be resolved by this approach; however, it was felt that the AIDS appropriation was not intended to address the universal concerns of the uninsured or underinsured.

Accordingly, the first step in devising a strategy to affect home care support involved (1) determining what impediments to the delivery of AIDS care were being experienced by existing service providers; (2) gathering recommendations on how best to target resources to alleviate access barriers and increase services; and (3) developing a programmatic and fiscal focus as a target for new funding initiatives. Over a period of several weeks during July and August 1986, meetings were held with representatives from Massachusetts visiting nurse agencies, hospice programs, home care agencies, trade association representatives, and others knowledgeable in the areas of community services and the needs of AIDS patients. More than fifteen meetings were held.

As a result of information gathered from these meetings, from talks with client services staff and with the supervisor of the volunteer “buddy” program at the AIDS Action Committee, and from a review of recent articles on AIDS home care, a model program was described for delivering home care services to patients with AIDS. This program description was then incorporated into the Request for Proposal issued to community agen-
cies that were providing home support services. A maximum obligation of up to $50,000 a year was noted as available to selected agencies for use in expanding their operational capacity to deliver AIDS care. These funds were not intended for use as entitlement funding for individual patients.

The RFP stated the intent to select agencies for funding which clearly indicated their commitment on behalf of using additional operational support to expand their capacity to deliver services. Funds were to be used to support direct care staff, supervisory or support staff, or staff whose services were not covered through third-party reimbursement. While other expenses might also be appropriate for state support under this program, priority was to be given to agencies that evidenced a strong commitment to use additional state resources to enhance or expand care for AIDS patients, in conjunction with maximizing third-party reimbursement for those patients with coverage.

In addition, the RFP noted that criteria for funding included the need for statewide allocation of resources; delineation of the geographic distribution and clustering of diagnosed cases of AIDS throughout the state; and an estimation of the expected demand for client services in the proposed program’s service area.

Home Health Initiative Program Components
The definition of a comprehensive home care program outlined in the RFP reflected two concurrent perspectives: that of the patient and that of the agency.

Patient needs. When a diagnosis of AIDS is made, hospitalization is usually required for testing and treatment. At the termination of the hospital stay, the patient is faced with decisions about further treatment and care. By its nature, AIDS is a disease that may incorporate a wide range of treatment and various modes of care. Much of this care and treatment can take place in an outpatient setting or in the home, provided that the appropriate services are in place. The care may range in type from the aggressive and curative to the palliative and respite. To provide this range of care, the RFP noted that the following should be available:

- A primary care giver (a family member, a significant other, or a mutually agreed upon person)
- A home health aide
- A medical consultant
- A skilled nurse (up to twenty-four hours per day)
- Physical, occupational, and speech therapists
- A volunteer or “buddy” (to prepare meals, run errands, and provide psychological support)
- A social worker/case coordinator
- A counselor/chaplain (to provide bereavement and spiritual counseling)
- A psychiatric consultant (to provide neurological evaluations/staff training on central nervous system [CNS] involvement)

The RFP stressed that to benefit the AIDS patient, a consistent and cohesive provision of care throughout the illness is imperative. This can most successfully be accomplished through a team approach, engaging the services of the persons in the preceding list, or
through provision of a consistent person to act as an advocate during the course of the illness, such as a social worker, nurse, or volunteer.

Agency needs. When a home care program is viewed from the agency perspective, a different set of issues is identified. AIDS patients have demanding physical ailments and a host of psychosocial problems. The infections associated with AIDS are usually multiple. There may be central nervous system involvement, with or without other diagnosed infections, which further complicates care.

Enabling a patient with AIDS to remain at home in the community requires the commitment and creative use of staff and resources by care givers and providers. Assurance of a comprehensive and consistent type of care for AIDS patients requires a multidisciplinary team approach. An essential component of any program is a detailed plan for the provision of emergency care and after-hours consultation, based on a prescribed protocol. The RFP recognized that in some agencies each of the identified components of the team might already exist; for other agencies, it might be necessary to identify other resources in the community in order to create the team. The team consists of the following providers:

- Homemaker/home health aide
- Nurses
- Social workers
- Therapists
- Medical consultant
- Psychiatric consultant
- Bereavement counselor
- Volunteers
- In-service training and support professionals

With a conceptual model devised and described in the RFP, copies were issued to all visiting nurse, hospice, and home health agencies in the state. In all, forty-three RFPs were distributed. Thirteen agencies responded, and eight were selected for funding to begin in January 1987. The contracts for these eight programs were renewed in FY '88 for $50,000 plus an increase for cost of living according to state purchase-of-service guidelines.

Residential Facilities

From documentation gathered by the community resource specialists as well as from ongoing discussions with providers, the AIDS Action Committee, and other patient advocates, it is clear that the need for housing resources for patients with AIDS is an overwhelming problem. During the course of the disease, the individual who is ill may have one or several acute episodes of illness requiring inpatient hospitalization in an acute care facility. Upon release from the hospital, the individual may return home and live in the community, though often in an increasingly debilitated state. Patients who are single, living alone, and unable to maintain an income may find it necessary to leave their apartment or house and live with relatives or friends. If this is not an option, then these patients may become dependent on advocacy resources.

In Massachusetts, the AIDS Action Committee maintains several houses that persons with AIDS or AIDS-related complex (ARC) may use in accordance with the policies and stipulations of the committee. Some of the individuals seeking housing are unable to comply with the house rules. These houses are not staffed; they are managed by the persons
residing in them, with support from the AIDS Action Committee’s housing supervisor. Therefore, individuals with active substance problems, central nervous system involvement (AIDS dementia), or other difficulties that may be disruptive to residents in the house are impossible to place in these facilities.

Recognizing that alternatives were needed for these individuals and that the state must assume more responsibility in meeting these needs, the Health Resource Office sought to develop a prototype staffed residential facility for use by individuals with AIDS or ARC. During FY’87, a facility was actually opened under contract to the Commonwealth of Massachusetts.

After obtaining permission to use a house on the property of the Western Massachusetts Hospital in Westfield, one of the Department of Public Health hospitals that had recently become vacant in accordance with new state rules regarding the use of such property, the Health Resource Office identified a local human service agency and requested its involvement in developing the facility and managing it as a residence for individuals with AIDS. Under a contract negotiated with the Jewish Family Services of Greater Springfield, a program for housing up to five persons in a facility staffed twenty-four hours per day was implemented. Individuals housed in the facility may be in a transitional phase and can live in the house until stabilized, or they may be unable to leave, in which case they will live in the house until the terminal phase of their illness.

A unique feature of the program at Western Massachusetts Hospital is its eighteen-bed palliative care unit, in which AIDS patients residing in the house may elect to be placed during the final stage of illness. Duplicating this model, particularly in the Boston area, will be difficult, owing to the lack of available property and the high cost of an appropriate site.

The need to find an appropriate residential setting for children who are ill with AIDS or ARC and whose parents are unable or unwilling to care for them was addressed during FY’87 through a joint venture between the Massachusetts Department of Public Health and the Boston Department of Health and Hospitals. By December 1987, twenty-four cases of pediatric AIDS had been reported in Massachusetts.

Using space owned and operated by the City of Boston, a contract was negotiated between the Boston Department of Health and Hospitals and the Massachusetts Department of Public Health to house four children in a twenty-four-hour staffed facility, with social worker and nurse practitioner time included to ensure continuity of care for the patients. While preference is given to placing these children with family members or in foster care, the pediatric residence assures that children will not be forced to remain inappropriately in an acute hospital bed until more suitable arrangements can be made.

During FY’87, while plans for the Western Massachusetts Hospital facility and the pediatric residence were under way, attention was directed to the plight of individuals with previous mental health histories who were homeless and had become infected with HIV. It was recognized that these persons posed special problems and that placements for them were at times impossible to secure. The staff of the Health Resource Office convened representatives from the City of Boston, the Robert Wood Johnson Health Care for the Homeless Project, the Pine Street Inn, the Lemuel Shattuck Hospital homeless shelter, and the AIDS Action Committee to address the growing concern about these individuals. Using documentation of several cases that fell into this category, the community resource specialist outlined the contacts that had been made and the steps taken to try to find an appropriate service for these persons. The role of the Department of Mental Health in caring for them was considered as an additional concern. Several issues were raised in
this context by the Department of Mental Health, including (1) whether it was able to ensure appropriate infection control precautions; (2) whether the patients would be more appropriately assisted by a medical service than in a Department of Mental Health facility, since their dementia was the result of organic disease and could not be expected to be responsive to traditional psychiatric interventions; and (3) whether the mental conditions experienced by AIDS patients were irreversible and therefore not the proper focus for the Department of Mental Health.

In addition to concerns about these patients, issues were raised about finding an appropriate placement for individuals with HIV infection who were homeless or actively using drugs or engaging in prostitution, or a combination of these. After consideration of the legal, social, economic, and ethical implications of these complex situations, it was felt that two objectives required an immediate response. Individuals with these complex social and medical problems needed to be placed in an environment that met their basic needs and that was conducive to helping them understand their infection and the need to observe infection control precautions at all times in order not to infect someone else; and a public response was needed to provide resources and an appropriate service for this difficult-to-serve population.

Building the Continuum of Care

In allocating resources in the midst of a crisis as large and overwhelming as the AIDS epidemic, a major tension arises, stemming from the need to have in place a plan of action based on future projections of need while at the same time responding to the call for immediate action. State funds are allocated for a one-year period. Funds not spent during that time are usually reverted. Not only does this raise concerns for the next year's allocation, but in addition, advocates are likely to attack politically sensitive administrators for their lack of action during a crisis.

In recognition of these factors, the Health Resource Office pursued a dual course of action. While working to assess unmet need and develop a process and structure for establishing priorities for funding, the office undertook simultaneous efforts to allocate existing resources to those areas where there was a consensus of need. These latter efforts have been described above. What follows is a description of the conceptual model for a continuum of care which was developed by the Health Resource Office and which was presented to the Massachusetts Governor's Task Force on AIDS, to be used in developing a five-year plan.4

Many of the health, social, and emotional support services needed to respond to the growing number of AIDS patients in the Commonwealth are already in place. However, their distribution throughout the Commonwealth may be uneven. The model is most useful as a basis for discussion among community leaders as they assess their own preparedness for addressing AIDS prevention and care.

Prevention

Preventing the transmission of HIV is the only currently available method of curtailing the epidemic. Therefore, the first component on the continuum of AIDS care consists of education and outreach services so that those who are at risk of exposure can be alerted to their risk status, assisted in obtaining additional information, and supported in changing risky behaviors.

Providing simple factual information is an important part of prevention efforts. This
includes directions to services; notification of educational programs, including television and print media efforts, public programs, and special advocacy events; and resources for further information or assistance.

Awareness education is also an element of AIDS prevention activities and is intended to provide substantial information about the virus; its effect on the body’s immune system; the meaning of antibody status and blood tests; current medical interventions; transmission of the virus; and methods to prevent exposure.

The third focus of AIDS prevention activities is risk-awareness education. This is intended to reach those individuals whose behaviors place them at high risk for exposure to the virus, and it includes specific knowledge of how to prevent initial infection and transmission of HIV.

The fourth category of the prevention component is training and in-service education. Through the efforts of the Health Resource Office staff, a trainer-of-trainer model has been pursued to ensure that health and social service professionals throughout the state are well versed about AIDS and that they incorporate AIDS awareness and education into their programs and client meetings.

**Clinical Transition**

The second component on the continuum of AIDS services is referred to as clinical transition. This is intended to help those individuals who may have been exposed to the virus and who require access to medical, social, and support services for detection and treatment and for the provision of care. Counseling and testing are critical pieces of this component.

**Patient Care Services**

An individual who is in fact infected with HIV will require patient care services, the third component on the continuum, during the course of his or her battle with the disease. In order to provide the full spectrum of services, both hospital- and community-based services will be needed.

Medical evaluation for seropositive adults and children, and diagnosis for those who are symptomatic, should be available in a variety of settings, including community-based medical practices and hospital outpatient and inpatient services.

Physicians from a range of specialities and in a range of settings should be well versed in HIV infection, as should other health providers.

Hospital services need to be appropriately distributed throughout the state, with the capability to treat the array of medical, neurological, and emotional problems experienced by those with HIV infection. As well, inpatient units capable of treating both the medical and psychiatric manifestations of the illness are a critical part of patient care services.

**Community-Based System of Care**

The fourth component on the continuum is a strong community-based system of care. This will enable those who are ill to remain at home as long as possible when not in an acute phase of the illness. A strong home health care service, able to provide nursing care and homemaker services as well as help with activities of daily living, is essential. Specialized care that includes IV therapy and other medical services will enable patients to stay out of the hospital for longer periods of time.

A full range of housing resources is going to be needed to support the individual’s
capacity to maintain maximum self-sufficiency during the course of illness. As well, specialized housing needs exist for particularly vulnerable persons, such as those with children or persons with central nervous system infections. Housing needs include emergency shelter; independent living in shared, group, or single-family housing; and supervised housing.

Other specialized services may need to be adapted or developed for treatment of those at high risk of exposure to HIV. Of particular concern is the need to develop services for intravenous drug users who seek to eliminate needle use, but these services must also address immediate methods for reducing the drug user’s potential exposure to the virus. The existing system of drug treatment programs represents a critical element of the community-based system of care. These programs need to be expanded and supported in order to intensify AIDS prevention efforts.

Public Health Policy and Planning

The fifth and final component of the continuum consists of the public health and research efforts needed to continue to address surveillance and monitoring, treatment, and policy development and implementation. Consensus of thought may not always be achievable among persons whose professional or advocacy experience has dealt with the complex issues of providing care and service to those who are ill with AIDS or ARC. The role of government, therefore, is important in forging strong partnerships wherever possible on the federal, state, and local levels among government, physicians, health and social service providers, and concerned and compassionate volunteer organizations such as the AIDS Action Committee to ensure that debate and discussion on the issues are focused and directed toward specific goals. The preceding outline of a continuum of care, it is hoped, will provide a focus for that effort.

Community-Based Development of a Continuum of AIDS Services

With a conceptual model in place which defines the services needed to prevent transmission of HIV and to provide care for those who are infected and ill, it is essential to form community networks of public health officials, health and social service providers, medical personnel, and community leaders, with particular emphasis on those community leaders who represent high-risk groups, educators, the media, and elected officials.

Initially, an assessment of the impact of the epidemic in the community will need to be made. Using epidemiological information from the state, including a breakdown of cases by risk factor, an understanding of the community risk potential can begin to be made. Through conversations with community leaders and service providers, an estimate of the number of individuals at high risk for exposure can be developed. Working with epidemiologists, a projection of case load can be developed as a benchmark for future planning efforts.

Using the conceptual model as a basis for discussion among the community leadership, an assessment of the applicability of the model to the individual community can serve as the beginning of a dialogue on a range of AIDS-related issues. As a focus for discussion, the conceptual model allows the provider community to be fully involved from the beginning and underscores the crucial concept that to be effective, AIDS planning and program development must be based on scientific and medical evidence, not on the community’s fear and lack of knowledge.
Once the community’s leadership shares the concept of the components needed to provide a continuum of care, an assessment of the services currently available in the community can be conducted. Information obtained as part of this effort will include the location of services; the capacity for care; barriers to care, such as a waiting list, residency requirements, language barriers, cost, and other factors; planned changes, such as expansion or relocation; sources of support; community sensitivities, and so on.

Conducting a comparison of existing services with the conceptual model will indicate to a community where gaps in service exist. Factoring in epidemiological projections for expected case load by risk group will help in determining priorities for resource allocation, which in turn will lead to decisions on whether to develop a new service or expand an existing one. In some instances, though a gap in service may be evident, a community may determine that since there is little need for that particular service, no resources or planning effort will be directed toward filling the gap.

Once priorities have been established, new resources can be sought through a range of means, including the efforts of individual providers to seek new funds; local initiative to attract state or federal resources; and advocacy to expand third-party coverage for specific services.

Community-based planning must work in tandem with state policy and with resource-allocation initiatives. Through increased information on community needs and priorities, state initiatives can better serve local communities in their efforts to prevent transmission of HIV and to provide care for those who are ill.

Notes


2. The FY’87 resource allocation plan was the subject of a June 1986 memorandum from Bailus Walker, Jr., then commissioner of the Massachusetts Department of Public Health and chairman of the Massachusetts Governor’s Task Force on AIDS, to the members of the task force.

3. The articles on AIDS home care referred to here were published in Caring, AIDS and Home Care 5, no. 6 (National Association for Home Care, Washington, D.C., June 1986).
