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Community-Based Case Management For Persons With AIDS

by Vincent Mor, John Piette; and John Fleishman

Early diagnosis and longer survival times for persons with acquired immunodeficiency syndrome (AIDS)– both evidence of progress in medical science–have produced a growing human immunodeficiency virus (HIV)-infected population requiring substantial medical and social intervention over a longer period of time. Case management has emerged prominently among the various strategies proposed to deal with the wide-ranging health care, psychiatric, and social service needs of people with AIDS and HIV infection. Most definitions of case management point to certain functions and activities performed by case managers, including client intake and assessment, service planning, referral and system linkage, and monitoring service receipt and client status. Many case managers also act as advocates on behalf of clients, aiming to get all services for which a client is eligible without consideration of cost or competing needs of others in the system.¹ No standardized definition of case management exists, and the role of the case manager varies significantly depending upon which of these tasks are emphasized.²

Case-managed systems of care have two primary goals. First, linking clients with appropriate community-based services should increase the length of time the individual remains in the community. Second, “rationalizing” the provision of services reduces inappropriate use of expensive inpatient care and total cost of care. Whether or not case management achieves these goals remains unresolved. Some studies have documented significant increase in occupational functioning, number of services received, and social integration associated with case management.³ However, one study showed no relationship with change in the number or severity of clients’ problems.⁴ The financial benefits of case management

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are equally indeterminate. Some experiments have shown a decrease in inpatient utilization and subsequent total costs.\textsuperscript{5} Other evaluations have concluded that by increasing access, case managers stimulate utilization and thereby increase the cost of care.\textsuperscript{6}

Early reports on health services use and associated costs of AIDS patients’ care attributed most costs to intensive and lengthy inpatient stays.\textsuperscript{7} Costs and length of hospital stay in San Francisco, where community support services for AIDS patients reach a large proportion of the affected population, are markedly lower than in many East Coast cities. These data have contributed to the assumption that community support could work to reduce costs for AIDS patients elsewhere.

Suppositions such as these have been a feature of U.S. health policy for nearly thirty years; they have been the hallmark of policies that include deinstitutionalizing the mentally ill, preventing nursing home placement of the elderly, and taking many aspects of medical and surgical service out of the hospital.\textsuperscript{8} While there is only limited empirical evidence that community care costs less, the compelling logic of the argument has shaped virtually all health policy debates on acute and long-term care.

The Robert Wood Johnson Foundation’s AIDS Health Services Program (AHSP) follows in this same tradition of fostering the development and integration of health service networks to minimize the inappropriate use of inpatient care. The original premise of the demonstration program was that the community approach is both more desirable and more cost-effective. Case management is a central feature of all funded projects. Programs established to provide community-based case management services for people with AIDS face enormous challenges. The purpose of this essay is to present preliminary information derived from an ongoing evaluation of the AIDS Health Services Program to elucidate major challenges facing the development and implementation of case management systems for persons with AIDS. Based on these challenges, we propose several policy and programmatic recommendations.

**The AIDS Health Services Program**

After considering applications from communities across the country, The Robert Wood Johnson Foundation chose a group of high-prevalence regions in which to stimulate the development of community-based programs to meet AIDS patients’ needs. (Similar efforts have since been fostered by the Health Resources and Services Administration, as well as other government and private agencies.)

Nine projects in eleven communities—Atlanta; Dallas; Fort Lauderdale, West Palm Beach, and Miami, Florida; Jersey City and Newark,
New Jersey; New Orleans; New York City and Nassau County, New York; and Seattle—were funded in late 1986 to serve as models for other communities across the country. The projects vary greatly in organizational structure. State or county governments sponsor projects in Seattle, New York City, and New Jersey; well-established community umbrella agencies are sponsors in Dallas and New Orleans; and community AIDS service organizations are sponsors in Atlanta and West Palm Beach. Moreover, the locus of project leadership in service provision also differs across projects. Hospitals are the principal actors in Newark, Jersey City, Nassau County, and Miami, while community-based agencies direct the projects in Dallas, New Orleans, Atlanta, and West Palm Beach.

The AHSP seeks to develop and coordinate specialized health and supportive services for persons with disabling HIV disease. At the level of the system of agencies providing service, the program’s goals include (1) funding and initiating new services for people with AIDS or AIDS-related complex (ARC), particularly community-based services; and (2) developing networks of human services agencies to minimize duplication and encourage coordination among providers. The emphasis is on community-based care, premised on the assumption that patients prefer such alternatives to extended inpatient care and that community-based systems of care will have lower costs than institutional approaches.

Regardless of program structure, a major component of the AHSP in each community is to provide case management services. From the perspective of the AHSP, the goals of case management include (1) increasing access to services; (2) enhancing service coordination and continuity of care; (3) identifying gaps or barriers to service delivery; and (4) increasing clients’ satisfaction. In theory, case management will achieve these goals because case managers link clients with needed social and medical services. Clients benefit because case managers are often aware of a wider array of services than are clients, and they have experience in maneuvering through the often complex system of application and eligibility determination.

Rosalie Kane has distinguished client-centered from system-centered case management. The client-centered perspective emphasizes satisfying the client’s service needs; cost containment is secondary. The system-centered approach focuses on allocating resources efficiently. In this approach, which is often termed “managed care,” the case manager determines whether clients’ needs justify receipt of costly services. Often, the case manager can authorize or withhold payment for services. According to Kane, system-based case management “serves a rationing and priority-setting function by husbanding resources. . . .” Case management in the AHSP clearly operates from the client-centered perspective,
Case management has already been established for populations such as the frail elderly, the developmentally disabled, and the chronically mentally ill. Case management for such groups is challenging, but, for people with AIDS, the task presents additional difficulties. Among the obstacles to developing an effective case management program for people with AIDS are the following: (1) adapting community-based case management to the different needs and demands of the different risk groups; (2) providing effective case management in the context of a burgeoning caseload; (3) coordinating care given the erratic course of the disease and the often sudden medical and psychosocial crises that arise in patient care; (4) meeting the community care needs of this population given the current capacity and willingness of traditional home health agencies and hospices to serve people with AIDS; (5) developing the necessary range of housing alternatives given current community resources; and (6) sustaining the burden of continued care through volunteer systems, particularly for the socially disadvantaged.

Data And Methods

Our observations of the challenges facing case management for people with AIDS are based on two sources of information. First, we obtained detailed quantitative and qualitative information about the process of program implementation during site visits to the funded communities between February and July 1988. We interviewed administrative and clinical staff in several participating agencies concerning services delivered, gaps in services, and the process of interagency coordination.

Second, we analyzed data from management information systems in each site. Case managers at agencies participating in the AHSP complete an intake form at the time they conduct an initial client assessment. The client intake form contains selected demographic information such as age, sex, racial and ethnic group, risk group, residential arrangements, employment status, and insurance coverage. Diagnostic information as well as dates of infection and diagnosis are also requested. The form also includes a rating of the client’s current physical functioning. The collection of intake data began in October 1987 and is ongoing.

These intake data provide a valuable source of information to site administrators and program planners. They also serve as a key source of information on the types and needs of clients within each case management system. To make this information more accessible, the evaluation team at Brown University designed a computerized management information system, which provides sites with the capability to aggregate intake data for administrative purposes as well as to fulfill the founda-
tion's reporting requirements. This system enables each project to describe all clients served and the general types of services their staff recommend for clients when they are admitted to the projects. All programs use either the system designed by Brown or an alternative designed by the site itself that provides similar information.

At present, intake data on 9,015 clients have been analyzed. Limitations of these data must be kept in mind. The number of completed intake forms per site does not necessarily represent the full number of clients served. Many sites have more than one point of program entry (for example, through the associated hospital and community-based organization). Poor communication between these agencies can result in differential underreporting of some client groups. Quality of records varies from site to site. Some sites have applied no quality control, while others review each case record. Our own internal consistency analyses reveal large numbers of records with missing information, particularly on the diagnostic and disease state items. Since employees responsible for maintaining these records may be unfamiliar with the Centers for Disease Control (CDC) classification system for HIV-related illness, these data are at times inconsistently reported or skipped completely. Despite these obvious limitations, the data do characterize the clients seeking assistance from these programs and, as such, provide a frame of reference for understanding the challenges facing the agencies and, particularly, their case management staff.

**Results Of The Evaluation**

**Client mix and service coordination.** Clients vary substantially from site to site (Exhibit 1). In four projects, the clients are predominantly gay or bisexual males; in the other projects, the clientele includes many intravenous (IV) drug users and their partners and children.

Within sites, the range of problems that clients present as they enter the program is substantial. Even in sites such as Dallas, where the clientele is predominantly gay white males, clients’ resources and needs are heterogeneous. In Dallas, 36 percent of the clients live alone, 57 percent are uninsured, and 79 percent are unemployed. Additionally, almost half (46 percent) of all clients entering the Dallas program require assistance with everyday activities. Conversely, others are well enough to be employed. While only 3 percent of Dallas clients enter the program in a Class I or II disease stage (that is, pre-ARC), 65 percent are in Class IV, the vast majority of whom have frank AIDS (Exhibit 2). Clients in these different disease stages vary in their needs for emotional support services versus concrete social services.
### Exhibit 1

**Characteristics Of AIDS Health Services Program Clients From Programs’ Management Information Systems, Valid Percentages, September 1989**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>New Jersey (n = 2,258)</th>
<th>Nassau County (n = 705)</th>
<th>Atlanta (n = 1,894)</th>
<th>Miami (n = 1,241)</th>
<th>New Orleans (n = 671)</th>
<th>Dallas (n = 618)</th>
<th>Seattle (n = 618)</th>
<th>Ft. Lauderdale (n = 255)</th>
<th>West Palm Beach (n = 964)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>75.4%</td>
<td>77.5%</td>
<td>93.3%</td>
<td>74.9%</td>
<td>93.5%</td>
<td>98.1%</td>
<td>95.8%</td>
<td>82.0%</td>
<td>77.3%</td>
</tr>
<tr>
<td>Gay/bisexual</td>
<td>13.3</td>
<td>0.1%</td>
<td>11%</td>
<td>17%</td>
<td>71%</td>
<td>84.4%</td>
<td>71.9%</td>
<td>89.1%</td>
<td>73.3%</td>
</tr>
<tr>
<td>IV drug user</td>
<td>62.0%</td>
<td>40.0%</td>
<td>8.9%</td>
<td>27.4%</td>
<td>7.3%</td>
<td>5.3%</td>
<td>5.6%</td>
<td>19.1%</td>
<td>22.7%</td>
</tr>
<tr>
<td>AIDS or ARC</td>
<td>79.3%</td>
<td>94.6%</td>
<td>83.3%</td>
<td>88.1%</td>
<td>82.0%</td>
<td>91.3%</td>
<td>91.8%</td>
<td>61.4%</td>
<td>74.4%</td>
</tr>
<tr>
<td>White</td>
<td>35.0%</td>
<td>74.9%</td>
<td>62.1%</td>
<td>88.8%</td>
<td>74.3%</td>
<td>89.0%</td>
<td>90.0%</td>
<td>68.4%</td>
<td>64.2%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>81.8%</td>
<td>80.6%</td>
<td>61.8%</td>
<td>61.3%</td>
<td>74.9%</td>
<td>78.9%</td>
<td>83.4%</td>
<td>85.3%</td>
<td>79.1%</td>
</tr>
<tr>
<td>Uninsured</td>
<td>12.0%</td>
<td>22.0%</td>
<td>58.4%</td>
<td>67.1%</td>
<td>53.3%</td>
<td>57.2%</td>
<td>33.3%</td>
<td>62.8%</td>
<td>30.4%</td>
</tr>
<tr>
<td>Live alone</td>
<td>16.8%</td>
<td>24.0%</td>
<td>38.2%</td>
<td>32.5%</td>
<td>10.8%</td>
<td>35.8%</td>
<td>33.3%</td>
<td>32.2%</td>
<td>22.7%</td>
</tr>
<tr>
<td>Poor functioning</td>
<td>40.3%</td>
<td>24.2%</td>
<td>21.8%</td>
<td>23.5%</td>
<td>35.2%</td>
<td>46.0%</td>
<td>68.7%</td>
<td>54.4%</td>
<td>35.1%</td>
</tr>
<tr>
<td>Alone and not insured or employed</td>
<td>5.3%</td>
<td>5.0%</td>
<td>14.9%</td>
<td>16.4%</td>
<td>10.2%</td>
<td>16.5%</td>
<td>7.3%</td>
<td>16.0%</td>
<td>7.0%</td>
</tr>
</tbody>
</table>

Source: Aggregate MIS database from The Robert Wood Johnson Foundation AIDS Health Services Program.

- More than 25 percent missing.
- Gay/bisexual male intravenous (IV) drug users are included in this category.

### Exhibit 2

**Estimated Disease Stage By Site, September 1989**

<table>
<thead>
<tr>
<th>Site</th>
<th>Class I: Acute HIV infection</th>
<th>Class II: Asymptomatic</th>
<th>Class III: PGL/ARC</th>
<th>Class IV: AIDS</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Jersey</td>
<td>2.4%</td>
<td>12.5%</td>
<td>10.3%</td>
<td>46.9%</td>
<td>27.8%</td>
</tr>
<tr>
<td>Nassau County</td>
<td>2.3%</td>
<td>2.8%</td>
<td>5.0%</td>
<td>84.4%</td>
<td>5.5%</td>
</tr>
<tr>
<td>Atlanta</td>
<td>0.0%</td>
<td>14.5%</td>
<td>3.6%</td>
<td>81.8%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Miami</td>
<td>0.3%</td>
<td>4.1%</td>
<td>7.2%</td>
<td>23.5%</td>
<td>65.2%</td>
</tr>
<tr>
<td>New Orleans</td>
<td>0.0%</td>
<td>17.5%</td>
<td>7.2%</td>
<td>73.5%</td>
<td>1.5%</td>
</tr>
<tr>
<td>Dallas</td>
<td>0.0%</td>
<td>2.7%</td>
<td>32.3%</td>
<td>64.8%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Seattle</td>
<td>0.6%</td>
<td>6.3%</td>
<td>2.8%</td>
<td>87.5%</td>
<td>2.8%</td>
</tr>
<tr>
<td>Ft. Lauderdale</td>
<td>1.6%</td>
<td>36.1%</td>
<td>11.4%</td>
<td>51.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>West Palm Beach</td>
<td>4.4%</td>
<td>20.7%</td>
<td>5.5%</td>
<td>67.6%</td>
<td>1.8%</td>
</tr>
</tbody>
</table>

Source: Aggregate MIS data from The Robert Wood Johnson Foundation AIDS Health Services Program.

- We classified PGL/ARC patients if they fit one of three conditions: (1) those patients with persistent generalized lymphadenopathy (PGL) and no other current or prior disease manifestations indicative of AIDS; (2) those patients who have been diagnosed with a CDC subgroup IVe disease (that is, “Other Conditions”) but not with any of the other CDC subgroup diseases (Iva to IVd) indicative of full-blow AIDS, and/or (3) those patients who have been diagnosed with a CDC subgroup IVc disease (“Secondary Infectious Diseases”) not on our list of fifteen secondary infectious diseases indicating full-blow AIDS.
- The Miami intake data categorized client diagnosis as either HIV-positive, ARC, or AIDS, differing from our standard format. In this exhibit, the three Miami categories are reported as asymptomatic, ARC/PGL, and AIDS, respectively.

Sites serving either clients with a diverse range of risky activities or a large proportion of clients who are IV drug users present even more striking examples of heterogeneity. For example, Miami serves a large proportion of persons of Haitian descent as well as a substantial number...
of IV drug users and gay and bisexual males. While 9 percent of gay/bisexual clients in Miami are unemployed, live alone, and lack insurance, nearly 21 percent of IV drug users and 17 percent of Haitians have these multiple deficits. Since a large proportion of these clients are asymptomatic at program entry, it appears that even relatively well clients present significant challenges to case management.

Serving this heterogeneous population presents complex questions for the case management approach adopted. Should case managers specialize in particular client risk groups or service needs? Are staff available who have had experience with both the IV drug-using population and the chronically ill? Who understands the broad range of casework issues, from Medicaid eligibility to methadone maintenance clinic services and policies? Specialization may increase efficiency and effectiveness; however, concentrating on any one client group or service need may increase the risk of “burnout” among generally underpaid staff.

In summary, at time of program entry, clients present highly variable needs. The needs of those still asymptomatic differ vastly from those of persons with disabling conditions. However, providing services for both groups may be equally labor-intensive. The broader the array of clients’ needs, the more complex the task of identifying them and arranging for delivery of appropriate services. Data from our survey of clients served within the program sites show large differences in the needs of various groups. Gay/bisexual clients are more likely to report a need for support groups and legal counseling, while drug-using clients are more likely to need residential placement and financial assistance. Case management staff must be able to identify the type of services needed by different groups of patients and the wide range of services available.

**Burgeoning case load.** Since their initial development, almost all projects have experienced an enormous growth in the number of clients receiving or registered to receive services. Data from case managers from each site regarding the current number of clients for whom they are responsible reveal enormous disparity. The three case managers in Atlanta are each responsible for an average of 142 clients, while in Miami, individual caseloads are as high as 200. Case managers in New Orleans, Dallas, and Seattle average forty, seventy, and sixty-four clients, respectively. Since the initiation of the program, many sites have experienced an increase in admissions without a concomitant expansion in clinical staff. For this reason, these caseload data are conservative estimates of the current burden on these professionals.

The observed variation in caseload from site to site is not solely a function of the size of the infected population in the area or the number of staff. Agency eligibility criteria also play a role. An examination of
Exhibit 1 reveals that in Atlanta, only a fairly small proportion of cases are in the poor physical functioning category (22 percent), while in Seattle, 69 percent of all clients admitted are in this category. Programmatically, Seattle has an explicit triage mechanism built into the client assessment process. Applicants without disabling HIV-related disorders are given short-term assistance to solve an immediate problem and referred to an appropriate support group. These types of cases do not remain on the caseload of a case manager but are referred to the volunteer network. Dallas experienced a substantial increase in case managers’ caseloads during the first year of operation and responded by developing and implementing a similar triage system. In contrast, in most other settings, all those seeking assistance who are HIV-positive are listed as clients. Case managers have no explicit policies for selecting the clients whose needs they should meet first. Without such guidelines, the most vocal rather than the most needy clients may be served.

**Monitoring clients’ needs over time.** Patients with HIV-related disorders present a complex and erratic clinical picture. Persons often recover full functioning following a near-fatal bout of *Pneumocystis carinii* pneumonia. The heterogeneity of different clients’ needs presents one set of problems for case managers, but the variability of this disease over time in a single individual presents a host of others that further complicate the case management task.

Unfortunately, we have no longitudinal information to estimate the rate of physical deterioration of clients once they enter the program; such information would help case managers estimate where in the course of the disease a client is and plan for service needs accordingly. Recent work by Barbara Turner and colleagues in establishing a severity classification system for AIDS will help clinicians better predict the number and type of problems they can expect from their overall caseload, even though patient-level prediction may as yet be impossible.  

To monitor the changing needs of clients, case managers need to contact them periodically. Such preventive monitoring could anticipate and allay concrete and emotional problems, thus minimizing the crisis-ridden experience of managing the medical, financial, and psychosocial burden of AIDS. Based upon our visits to each site, we found only a few have any organized approach to monitoring clients’ status. This lack of status-change information inhibits case managers’ planning for changes in their clients’ service packages.

### The Challenge Of Delivering Home Care

As revealed in Exhibit 1, many clients live alone. Long-term care
research has shown that living alone is one of the most important risk factors for institutional placement. Based on the relatively high proportion of clients in some sites who function poorly and are unemployed and uninsured, many will need some form of home care to remain in the community. Indeed, an estimated one-quarter of persons with AIDS living at home experience disease-related symptoms sufficiently severe to require home care, and some have needs that require hospice services.

Our own contacts with home health agencies in each site suggest that most have taken a strong stance in requiring all staff to work with persons with AIDS. Even the proprietary home health agencies take on difficult cases, despite the vast difference between these clients and the chronically ill elders whom they traditionally have served. However, there are barriers to the widespread use of home care for this population. The lack of social supports (particularly for IV drug users) and the intense physical and psychosocial problems associated with the disease hinder community treatment. In many areas of the country, these problems are compounded by a shortage of nursing and paramedical personnel.

The hospice movement also appears to have embraced people with AIDS in almost all participating sites. Nevertheless, philosophical and practical problems in delivering hospice care to such persons apparently remain to be solved. Hospices are not accustomed to working with patients with such an erratic disease course who may be undergoing active treatments to prolong survival, not merely to ameliorate symptoms. Hospice staff have reported that the case managers and volunteer agencies working with people with AIDS are uncomfortable discussing death with their clients, because it is linked to giving up hope. This lack of congruence between philosophy and patient needs may delay integration of hospice into the community service system for AIDS.

Housing capacity. Perhaps the most pressing need for persons at all stages of HIV infection is housing. Given the large proportion of people with AIDS living alone and with very limited income, most will require help with residential placement at some point in the course of their illness. Several factors impede the development of subacute facilities. Regulations in many states make it difficult to adapt nursing homes and other forms of institutional housing to the needs of people with AIDS. In addition, substantial community opposition has emerged concerning locating residences for people with AIDS. Some sites, such as New Jersey, experienced considerable neighborhood objection to the location of a subacute facility serving people with AIDS, and projects in Nassau County and New Orleans have gone to considerable lengths to keep the location of their fairly small housing programs secret.

Most projects proposed to develop housing options during the first few
years of the AHSP grant. New Jersey has failed twice to develop a specialized AIDS nursing home. Atlanta organized thirty-two “shared housing” arrangements for physically well clients, while Miami has twelve nursing home beds and six hospice inpatient beds available. Miami has also been able to organize a modified system of rental vouchers for residential hotels willing to accept people with AIDS. New Orleans arranged one residence that can accommodate sick patients, and Dallas has developed several residential options from temporary shelter to long term care for impaired persons who do not need hospitalization. Seattle has specifically designated staff resources to identify and arrange housing for clients. The Seattle project has developed five placements for seriously ill patients, and a group residence for more able clients has been approved and funded for the future.

Unfortunately, we have little information about the hospitalization rate or length-of-stay of people with AIDS in these programs. This makes it difficult to associate the availability of alternative, subacute housing with the use of hospital beds. Future analyses seeking to compare communities on this basis, however, will also have to consider the mix of clients in the program and the availability of home care.

The resiliency of volunteer systems. The role of volunteers in giving emotional and practical support has been a hallmark of the home-based care phenomenon in San Francisco. Exhibit 3 presents data on volunteer use in six sites. As can be seen, the sheer amount of volunteer service being provided is enormous. Unfortunately, it is difficult to determine precisely the number of clients being served during any one month. This means that estimating the number of volunteer hours available per client is tenuous at best. Nonetheless, it is clear that the sites with the highest level of volunteers have a high proportion of gay/bisexual clients (Dallas, Atlanta, and Seattle). In general, this is because most volunteers are gay/
bisexual men and because volunteerism has been difficult to implement in a predominantly IV drug-using population.\textsuperscript{16}

In those communities in which volunteer use is the norm, volunteers provide an amazing amount of help. Similar levels of volunteer effort occur in the hospice movement, particularly among the community based volunteer organizations. Among hospital-based hospices, volunteers served mostly on the inpatient units.\textsuperscript{17} It remains to be seen whether the home hospice and community-based AIDS volunteer system can be adapted to organizations such as the hospital-based coordinating centers being developed in New York City, New Jersey, and Miami.

In many sites with community volunteer programs, the volunteers are organized to work with clients outside of the case management system. Volunteers are not supervised, nor are their activities coordinated, by case managers. Most volunteers report to a director of volunteer services who is responsible for recruiting, training, and monitoring them. Since the volunteer coordinator and case managers are often employed by different agencies, it is possible that changes in volunteer services may be made without the case manager’s knowledge. Concerns about the confidentiality of the relationship between volunteer and client also can limit transfer of information about the client to the case manager. To complicate matters, in some locations, several volunteer agencies serve somewhat different functions, each with different pools of volunteers. These organizational arrangements rely heavily on the communication skills of volunteers and place significant pressure on whatever system case managers adopt to monitor the status of their clients.

### Discussion Of Key Case Management Issues

Several factors in the environment of community-based AIDS case management programs undoubtedly will influence their behavior in the years to come. Health care financing incentives, such as New York State’s Designated Center program, obviously will affect the structure of case-managed care for persons with AIDS. The extent to which patients are routinely “dumped” into public hospitals if they are not able to pay for their medical care also will influence hospitals’ willingness to assume a greater responsibility for developing home-based programs. Whether the level and type of community volunteer support is able to meet the growing need for care remains to be seen. Finally, if providers believe that being identified as the sole community repository for AIDS care threatens their solvency, they may be unwilling to become significant sources of care for this population.

A limitation of our study is a reliance on a voluntary, project-specific
management information system. While use of administrative data for research and analysis always requires caveats regarding the specific validity of observed relationships, established systems for billing or hospital discharges are subjected to some level of quality control. Management information systems designed especially for multisite demonstration projects have other problems. Most such projects aim to test the feasibility of a program concept for which there are no established models. Flexibility in implementing the concept is often paramount; the necessarily uniform definitions of a management information system may impose more structure than is desirable to retain the goal of flexibility. Also, projects are often housed in agencies with limited administrative sophistication.

Many of the projects were situated in new agencies or hospitals already buckling under the pressure of an increased clinical load. Foundation and program staff also decided that the benefits of uniform data were outweighed by restrictions that go along with imposed systems of eligibility determination and policies around client contact. Consequently, not all sites used the computerized data entry, management, and reporting system we developed, and only a few used it for internal project management. Data derived from programs that do not use them for any purpose other than reporting are likely to be less accurate than those used by program staff to plan and monitor services. Recognizing these limitations at the outset, the evaluation is assembling an independent database. Nonetheless, we feel that in several of the sites for which we present data, the data accurately portray the clients they purport to serve.

A major impediment to the provision of case-managed care is the dearth of many needed services including housing options, transportation, and drug abuse treatment slots. In several regions of the country facing a large population of indigent AIDS patients (such as New York or New Jersey), the lack of services is so constraining that even the most effective case management system may have only limited benefits. Such coordinating functions must necessarily be viewed in the context of the range of services available to be coordinated.

**Recommendations.** Although major challenges and impediments exist, community-based approaches should not be abandoned. These approaches are obviously consistent with the recent tradition of health services. However, can we achieve the goal in the long run without careful reconsideration of the strategies used? Failure to achieve our goals in the short term, as could certainly occur, may lead to the adoption of a thoroughly institutional approach. In light of this, we suggest that communities seeking to develop community-based managed care programs for people with AIDS consider the following recommendations.

(1) Community consortia should devote resources to developing a
continuum of housing options. As these data show, many people with AIDS lose their jobs, become disabled, and lose social supports, all of which increase their risk of impoverishment and displacement. Few cities currently possess housing options that can meet the often complex nursing care needs of this population. Thus, the development of a continuum of long-term housing placements is critical.

(2) If case management is adopted as a coordinating strategy, all relevant volunteer service information and general health services information must reside with case managers. Currently the administrative structures for case management and volunteer services are often separate within the provider organizations, or even provided by separate agencies. Given the large caseloads of case managers, volunteers are often the only frequent link between the client and the care system. To ensure that critical information on clients’ status and progress flows into the case management system, volunteer supports should be supervised under the rubric of the case management agency.

(3) Whether or not case management is adopted, explicit triage will be required for people with AIDS on the basis of need for concrete services such as housing, transportation, and homemaker services. Growing caseloads already are stretching resources beyond capacity in many areas. In the future, fewer services will be available per client unless clients with the greatest needs are identified and managed accordingly.

(4) Communities with large numbers of persons living alone and with limited financial and social resources may need to plan for specialized long-term care facilities for people with AIDS. While client advocates have feared the “internment camp” for AIDS since the epidemic began, provision of intensive and variable levels of nursing care in the home may not be possible in many areas as caseloads mount. San Francisco General Hospital and other acute care settings have shown that acute care for AIDS can be delivered in an effective, respectful, and humane manner through designated inpatient units. Similar facilities may be needed to accommodate the long-term needs of patients who are homeless or lack adequate social supports.

(5) Communities with strong existing home health services that adopt a case management model may be best served by locating the case managers in the community rather than in a hospital. Agencies in the community responsible for case management should have an administrative structure capable of monitoring the needs of clients and the services they receive, as well as maintaining the connections with appropriate health and social service providers.

(6) Communities with a relatively high proportion of people with AIDS outside of the gay community need to explore strategies to aid the
family in providing the support necessary to maintain individuals in the community. Since the volunteer pool available to the well-organized gay community is less available to groups such as IV drug users, relatives may be an alternative source of support. Often heterosexual AIDS patients live in impoverished communities; their families lack financial resources for their care. If the service system supports these families in meeting the many needs of their disabled relations, the demand for formal services such as housing, home meal delivery, and aggressive monitoring by case managers may decrease significantly.

(7) Finally, if a case management approach is to be adopted on a large scale, the role of case manager needs to be more clearly articulated, and a well-trained pool of staff is needed. Currently the process, goals, and definitions of case management vary across sites and across settings within sites. Few protocols exist, and evaluation efforts are just getting under way. Not surprisingly, the experience and training of staff providing case management varies as well. Effective case managers require training in entitlement programs, medical and psychosocial issues of AIDS, and the particular referral network and service providers within the area. Based on the experience of case management systems with other client groups (the elderly, mentally ill, or terminal cancer patients), as well as ongoing results of evaluations of AIDS case management systems, a sense of what works needs to be developed. This can then be put to use in the form of more specific job descriptions, training requirements, administrative models, and protocols.

Case management undoubtedly will play a significant role in the system of care available to people with AIDS in coming years. Many lessons can be learned from the experience of case managers working with other populations. However, the needs of people with AIDS are in many ways more complex and pose unique challenges to the health and social service systems on which they depend. Data from the evaluation of The Robert Wood Johnson Foundation’s AIDS Health Services Program provide insight into these challenges. If programs are to succeed, effort must be made to clearly articulate both the goals of provider agencies and the role case managers will have in meeting these goals.

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NOTES


10. Ibid.


13. Harrington et al., Long Term Care of the Elderly.


15. Special Commission on Nursing, Final Report, Department of Health and Human Services (December 1988).
