I. ESSAY

Developing AIDS Community Service Consortia

by Vincent Mor, John A. Fleishman, John D. Piette, and Susan M. Allen

The early years of the acquired immunodeficiency syndrome (AIDS) epidemic in the United States were marked by rapidly increasing numbers of young people dying from a bewildering array of exotic infections, often following lengthy and costly hospitalizations. A lack of knowledge about modes of transmission, combined with extreme prejudice against the populations at highest risk, engendered an aura of hysteria that impeded understanding and access to care.

By 1986, 21,570 cases of AIDS had been reported to the Centers for Disease Control (CDC); over half of these people had died. Urban hospitals were reeling under the human immunodeficiency virus (HIV) epidemic and the medical consequences of drug abuse and violence. The lifetime cost of AIDS was estimated to be $145,000 per person, almost all of which was associated with hospital use. Medicaid programs were facing unanticipated costs. A strategy was needed to reduce reliance on hospitals by developing outpatient treatment and community support services.

The Robert Wood Johnson Foundation (RWJF) initiated the AIDS Health Services Program in 1986 to develop integrated networks of human services agencies (consortia) and to coordinate the provision of services using case management. The program emphasized community-based care, inspired by the “San Francisco model,” which is based on the premises that patients prefer community care to hospitalization and that this approach is also less costly. This essay summarizes the program evaluation, with particular focus on the approach to organizing and delivering case management services.

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Evaluation Design

The goals of the program evaluation were to assess the feasibility of developing community-based services for persons with AIDS and to determine factors that facilitated or impeded service development and provision. We viewed program sites as examples of how communities were attempting to develop and coordinate the diverse health and social services needed by persons infected with HIV. Indicators of service development processes included interorganizational conflict and extent of joint programmatic activities, targeting of case management services, case manager contact frequency, and the types of client problems addressed by case managers. Indicators of program outcomes included expansion of community-based services and the fulfillment of clients’ needs for services.

The evaluation data collection strategy was complex; evaluators gathered extensive qualitative and quantitative information about each community in the program, as well as about the participating hospitals and community-based agencies and the clients served. During annual visits to program sites, administrative and clinical staff were interviewed. A management information system (MIS) was established to document clients’ characteristics upon entering the program. Interviews were conducted with a subsample of 1,386 clients to assess a variety of issues, including contact with case managers and the presence of unmet service needs.

Program And Population

The foundation selected nine projects located in eleven communities. However, because the New York City project was a coalition of community consortia and not a service-level consortium itself, we focus here on only the remaining ten communities (Exhibit 1). Consortia typically included a public or nonprofit hospital (with the exception of West Palm Beach and Fort Lauderdale) and a community-based AIDS service organization (CBO) providing mental health and social services, support from volunteers, and other services, such as home meals and housing allowances. The consortia were administered by either the hospital, the CBO, an existing nongovernmental agency, or a state or local health department. More than half of the communities had multiple community AIDS service organizations; in two communities at least one of the CBOs was minority focused. All consortia had member agencies involved in home care; in six settings a hospice was involved in service delivery from the outset.

Case management designed both to advocate for program clients as a group and to expedite service delivery to individuals was present in all sites, although its locus varied. In several sites case management was conducted
by both a hospital and a CBO.

The AIDS epidemic in each site varied substantially. For example, of the 808 CDC-reported AIDS cases in Newark in 1987, 25 percent were women, 60 percent were injected drug users, and 73 percent were black. In contrast, 85 percent of the 523 incident cases in Atlanta reported male homosexual contact with an infected partner as their sole risk factor for HIV infection; only 4 percent were women, and 30 percent were black.

Most program clients were enrolled at one of two entry points: the public hospital or the AIDS CBO. The two points of entry served different client populations. Clients admitted via CBOs were more likely to be gay white males than were the clients admitted via hospital clinics. Lack of health insurance represented a problem for the majority of clients in states having the most restrictive Medicaid policies (covering the Atlanta, New Orleans, and Dallas sites) and in communities where a large proportion of clients entered the program before their condition progressed to AIDS (Miami,
Fort Lauderdale, and West Palm Beach). The average annual population with AIDS in program sites increased 126 percent between 1987 and 1990, with increases ranging from 91 percent to 175 percent. During that period the average increase in the number of persons alive with an AIDS diagnosis in these eleven cities was 191 percent, ranging from 181 percent to 257 percent.

Accompanying this growth was a shift in the mix of clients served. Exhibits 2 and 3 present the growth in the number of new intakes into the MIS database per half-year broken down by risk group (homosexual versus heterosexual males) and by entry site. While 80 percent of all clients coming to CBOs were homosexual men in 1987, by 1990 this was true of only about 65 percent of new clients. The proportion of gay men coming to hospital clinic sites increased from about 33 percent in 1987 to more than 40 percent in 1990.

CBOs grew dramatically. Between 1988 and 1990 the average CBO budget increased by 215 percent, with one agency’s budget growing by 535 percent between 1987 and 1990. In particular, the number of case managers showed a remarkable increase. Most agencies experienced problems coping with growth. CBOs struggled to develop the administrative and budgetary systems needed to operate organizations having annual budgets exceeding $1 million. The nascent HIV service systems were strained by this rapid growth as well as by the changing complexion of the epidemic, evidenced by the increasing proportion of clients who were minority and female. The shifting demographics of the epidemic created pressures for new services and brought new entrants into the network of providers.

Exhibit 2

<table>
<thead>
<tr>
<th>Number of new admissions</th>
<th>Gay male</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>2,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1,500</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>500</td>
<td></td>
<td></td>
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<tr>
<td>0</td>
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</tr>
</tbody>
</table>

Source: AIDS Health Services Program Management Information System (MIS).
Exhibit 3
Changes In Risk-Group Distribution Of New Clients Entering The AIDS Health Services Program Via Community-Based Organizations, 1987-1990

<table>
<thead>
<tr>
<th>Number of new admissions</th>
<th>Gay male</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>800</td>
<td></td>
<td></td>
</tr>
<tr>
<td>600</td>
<td></td>
<td></td>
</tr>
<tr>
<td>400</td>
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<td></td>
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<tr>
<td>200</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Source: AIDS Health Services Program Management Information System (MIS).

Consortium Functioning

Most consortia experienced some degree of interagency conflict. Conflict between the CBO and the local public hospital compromised operations in four sites, and conflict between CBOs occurred in one. In one site interorganizational relationships broke down to the point that there was no structure to exchange information between the major hospital and the CBO at any level. Large hospitals and community-based AIDS service organizations were unaccustomed to dealing with each other as equals. Communication problems were often complicated by differences in service philosophy (medical versus social model) and by mistrust. Conflict was most evident in sites where a public hospital was the site’s lead agency. In such sites CBOs distrusted the hospital because it tended to allocate a disproportionate share of resources and decision-making authority to itself.

There was less conflict in consortia led by health departments, especially local health departments. Informants in several sites expressed the opinion that the lead agency should be seen as a neutral party. The lead agency’s authority in the consortium is facilitated if other members view it as providing a complementary (not competing) and valuable service. Lead agencies providing only case management found their authority undermined because some consortium members felt this service was unimportant.

Conflict between CBOs typically centered on differences in philosophy or clientele. In one site the consortium had to deal with persistent conflict between one agency providing centralized case management services and a second community agency wanting a greater allocation of funds for direct services. The sentiment that case management was a “frill” was expressed in...
other consortia, especially during negotiations over funding allocation.

Joint programmatic activity was minimal in most sites. Agencies in each consortium were expected to meet routinely to discuss common issues in service delivery, but many consortia held meetings erratically or on a pro forma basis. Reviews of minutes of administrative meetings of consortium members suggest that for the most part their focus was on information exchange rather than policy formulation. Consortium development was hindered in some sites by the administrative inexperience or instability of the lead agency. This was particularly the case for consortia headed by fledgling community-based AIDS service organizations. Several CBOs experienced turnover in top administrators; most had to struggle to develop an adequate administrative and fiscal infrastructure.

There were few instances in which a consortium collectively formulated and enforced a policy (such as written guidelines for client eligibility or for staff interchange) or acted as a decision-making body. It apparently was rare for consortium members to analyze jointly deficiencies in the service delivery system and to consider possible solutions. There were few instances of agencies changing their policies or operating procedures in response to suggestions from other members, and in no site were formal mechanisms established for adjudicating disputes among consortium members. The tenor of interagency relationships in most sites was best characterized by one observer who called it a “forced marriage.”

The program consortia had neither the structure, the authority, nor the incentive to address controversial or redistributive issues. We observed few attempts at service integration involving organizational restructuring, such as developing interagency programs or transferring staff from one agency to another. The agencies’ existing programs generally remained the same; similarly, the overall service delivery systems were rarely affected.

The Process Of Case Management

Eighteen organizations provided case management in AIDS Health Services Program sites. In some sites (Miami, Fort Lauderdale, Newark, and Jersey City) case management was conducted almost exclusively within the hospital or clinic setting, while in others (Atlanta, Dallas, and New Orleans) CBOs provided it. The remaining sites had case managers in both hospital and community settings.\(^6\)

The approaches to case management adopted by CBO- and hospital-based case managers were quite different.\(^7\) Hospital case managers emphasized discharge planning, obtaining entitlements, and making referrals to home care agencies. CBO case managers linked clients to emotional support programs, buddies, and other volunteers and provided assistance with
emergency housing and financial support.

For indicators of case management implementation, we focused on the extent to which clients were in contact with case managers. Specifically, we examined the proportion and characteristics of clients who said they had a case manager, the frequency of contact with case managers, and the types of problems presented to them.

**Caseload size and targeting.** By 1990 caseloads ranged from twenty-nine clients per case manager in Seattle to 290 in Fort Lauderdale, but in most agencies they averaged from fifty to sixty-five. Growth had occurred rapidly and early in the program. High caseloads arose in part from lack of triage policies. The development of explicit triage protocols to allocate case management resources occurred slowly. In the absence of a formal triage system, clients have been implicitly triaged as case managers devote more time and effort to the most needy clients. By the end of the demonstration, most agencies had adopted targeting.

We interviewed people receiving services at CBOs and HIV clinics. Although all respondents were potentially eligible for a case manager, some reported not having one (19.7 percent of CBO respondents and 46.1 percent of hospital clinic respondents). These results suggest some slippage (or implicit triage) in connecting clients to case managers, especially in clinic settings. Over time, the proportion of CBO clients with a case manager increased, but the proportion of clinic patients reporting a case manager declined.

Controlling for client entry point (that is, CBO or clinic), we observed no differences in the likelihood that clients had a case manager as a function of race or risk group. Women were less likely than men to report having a case manager, especially among clinic respondents (44.9 percent of females versus 55.7 percent of males). As can be seen in Exhibit 4, however, clients who reported needing services were more likely to have a case manager than were those without service needs. For example, of those recruited in a clinic who needed help applying for entitlements, 65.2 percent had a case manager, compared with 47.9 percent of clinic respondents who did not need such assistance. Similar patterns occurred for each service need listed in the exhibit, regardless of recruitment site.

**Contact frequency.** We found that clients with a case manager were contacted approximately monthly. While 15-21 percent of clients had no contact with their case managers in the last month, the same percentage had three or more contacts. Our examination of case management records revealed that 77.4 percent of case management contacts with clients were via telephone; home visits were rare. Minority clients, women, and injected drug users who had a case manager were contacted as frequently as their white gay male counterparts. Indeed, clients reporting that they needed
### Exhibit 4

**AIDS Health Services Program Patient Characteristics And Service Needs**

<table>
<thead>
<tr>
<th></th>
<th>Clinic-based case management</th>
<th>CBO-based case management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>55.7%&lt;sup&gt;a&lt;/sup&gt;</td>
<td>80.8%</td>
</tr>
<tr>
<td>Female</td>
<td>44.9</td>
<td>72.7</td>
</tr>
<tr>
<td>White</td>
<td>51.7</td>
<td>79.8</td>
</tr>
<tr>
<td>Nonwhite</td>
<td>56.3</td>
<td>83.0</td>
</tr>
<tr>
<td>Injected drug use</td>
<td>57.5</td>
<td>78.8</td>
</tr>
<tr>
<td>Nonuser</td>
<td>53.8</td>
<td>80.3</td>
</tr>
<tr>
<td>Help with entitlements</td>
<td>65.2</td>
<td>85.3&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>No help with entitlements</td>
<td>47.9&lt;sup&gt;a&lt;/sup&gt;</td>
<td>77.8</td>
</tr>
<tr>
<td>Help with rent</td>
<td>62.2</td>
<td>84.3</td>
</tr>
<tr>
<td>No help with rent</td>
<td>50.3&lt;sup&gt;a&lt;/sup&gt;</td>
<td>77.9&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Support group provided</td>
<td>62.6</td>
<td>84.7</td>
</tr>
<tr>
<td>No support group provided</td>
<td>50.5&lt;sup&gt;a&lt;/sup&gt;</td>
<td>75.8&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

**Source:** AIDS Health Services Program Evaluation.

**Notes:** AIDS is acquired immunodeficiency syndrome. CBO is community-based organization.

<sup>a</sup> p<.05  
<sup>b</sup> p<.10

assistance obtaining social services had more frequent contact with their case manager than did those who reported no need for assistance. Furthermore, our data suggest that contact frequency among those with a case manager increased as the program evolved.

**Problems presented to case managers.** Over 870 respondents were asked whether they had requested help with a problem from their case manager in the preceding three to four months. Of those with a CBO case manager, 62 percent had brought a problem to the attention of that person. For 60 percent, help was needed in obtaining entitlements such as Medicaid or Supplemental Security Income (SSI); issues concerning receipt of medical care (19 percent), emotional support (23 percent), legal assistance (11 percent), and housing (12 percent) occurred less frequently. Of those with a clinic case manager, 48 percent had sought assistance from their case manager. For 47 percent of these respondents, the problem involved assistance with entitlements; problems with medical care (24 percent) or emotional support (15 percent) were notable but less frequent.

Clients’ evaluations of their case managers were very positive. Furthermore, clients’ sex, race, or risk group was unrelated to their satisfaction with case management. Clients were somewhat happier about their case manager’s personal attributes than their availability, but this is not surprising given case managers’ large caseloads.
Outcome Of Service Development Efforts

The comprehensive networks of out-of-hospital services for HIV-disease patients that were proposed by all grantees included ambulatory clinic services, home health services, and housing, including long-term care. We examined whether these services were more readily available in each community by the end of the demonstration than at its outset.

The ten ambulatory HIV clinics participating in the program experienced an average increase in caseload of 306 percent between 1988 and 1990. All but one markedly increased the number of hours they were open for patient treatment, and all but one increased the number of physicians working in the clinics. In 1988 access barriers to home care services were often reported, despite the availability of funds to pay for these services. By 1990 these barriers had largely been overcome. A survey of 236 home health agencies from all ten sites revealed that over 70 percent had served at least ten persons with AIDS; generally, two or three agencies served over half of reported HIV-positive home health users in each city.

Nursing homes, inpatient hospices, sheltered residential care, subsidized apartments, and rent subsidies were in great demand in all sites—38.9 percent of surveyed clients reported need for housing assistance. Lack of housing precluded receiving home health services and complicated client monitoring by case managers. By dividing the number of available long-term care beds (for example, nursing home, residential care, special apartments) into the number of persons living with AIDS (from CDC reports), we found that there was an average of fourteen persons with AIDS per bed across all sites. Seattle and West Palm Beach had the most abundant available housing options (6.3 and 5.6 persons per available bed, respectively). New Jersey and Miami had nursing homes, board and care homes, and subsidized apartments available (17.3 and 13.0 persons per available bed, respectively), and Dallas concentrated fifty-nine of its eighty beds in subsidized apartments (11.6 persons per available bed). Thus, the program sites were apparently able to overcome barriers to housing for their clients.

Client outcomes. Elsewhere we have reported that among program clients, women and minorities used less outpatient care and spent more time in the hospital than did white males. We also examined the relationship between case management and resolving clients’ needs for assistance and whether over the course of the demonstration clients’ needs were more likely to be resolved with case management. In general, we found little improvement in the overall rate of unmet need for various social services over time. Indeed, in spite of the greater availability of both home health services and alternative housing in the relevant communities, there was no reduction in the rate of unmet need. However, those clients with a case
manager reported less unmet need, particularly for help in securing entitlements such as disability assistance and Medicaid. Since CBO clients were more likely to be linked to a case manager than were clinic patients, their needs were more likely to have been resolved.

Discussion

The men and women who attempted to build a network of coordinated services for persons with HIV disease faced an extremely difficult task. There was a substantial increase in the scope of the epidemic as well as change in the racial, sex, and risk-group composition of HIV-infected persons during the course of the demonstration. Program staff had to cope with a confusing state and federal policy environment, complicated by changes in medical treatment and in the conceptualization of AIDS. In 1986 AIDS was still perceived as an acute, fatal illness, and policies for expanding terminal care benefits were the focus of discussion. The focus has now shifted to early intervention and ongoing treatment programs for a new chronic disease. The organizational and policy implications of the rapidly evolving epidemic must be kept in mind in considering the lessons to be garnered from the AIDS Health Services Program experience.

Our discussion of what can be learned from the program addresses two issues. First, were the consortia and their attempts at individualized case management and service development effective? Second, what are the implications for similar consortia seeking to coordinate service delivery to other chronically ill populations using case management?

Program effectiveness. Most consortia experienced internal strife that compromised their effectiveness. Whether this strife was attributable to turmoil experienced by rapidly expanding CBOs or a clash of cultures in the interactions of hospitals and community-based groups, the result was impaired efforts to engage in collaborative activities at the organizational level. Effective coordinated action requires consensus on service priorities, belief in the value of all agencies’ roles, and the authority to implement unpleasant reallocation decisions. Perhaps it is unrealistic to expect groups with different perceptions of the problem to engage in joint planning and to achieve a harmonious allocation of resources and responsibilities.

More fundamentally, it may be extremely difficult to persuade either public hospitals or community-based agencies to cede control of activities when they perceive those activities to be central to their mission. If rational reallocation for efficient consortium functioning requires actions contrary to members’ perceived mission and organizational survival, tensions will be heightened and cooperation limited.

Case management was adopted as the strategy for enhancing service
coordination by virtually all CBOs involved in the consortia and by many outpatient HIV clinics. This strategy has not been restricted to RWJF programs; most AIDS CBOs in the country have adopted case management, and it is explicitly written into the Ryan White CARE Act (P.L. 101-381), which is the federal government’s approach to funding services for persons with AIDS. We found that even in the face of interagency conflict, agency staffs regularly communicated concerning problems of individual clients. However, not all members of the consortia valued case management; specifically, some clinics did not routinely refer to case management, and some CBOs decided that their appropriate emphasis should be advocacy or actual service provision rather than “coordination” of care.

In many program sites, procedures for client selection, monitoring, service provision, and documentation were loosely structured. Particularly in the early years, written qualifications for case managers were often absent; formal job descriptions varied considerably from what staff reported doing; detailed manuals outlining case management practice standards were unavailable; and patient-level documentation was often sketchy. Further, the program did not impose uniform case management: procedures across all agencies. This led to differences in implementation between hospital clinics and CBOs. Finally, rapidly expanding caseloads forced case managers in many agencies to adopt a crisis-resolution mode and inhibited proactive service planning and thorough client monitoring.

Those clients who had a case manager appreciated the assistance and reported finding solutions to some of their problems. Clients who reported needing social services were more likely to have a case manager than were those without service needs, suggesting a naturally occurring triage process. However, substantial proportions of eligible clients were not linked to the case management system, and many clients used case management primarily to obtain entitlements.

Despite the limitations in consortium operations and in the delivery of case management, expansion of needed services did occur. Most cities ultimately were able to develop an array of housing alternatives sufficient to serve approximately one out of fourteen CDC-reported cases of AIDS. However, a review of housing availability in twenty nonprogram cities across the country with moderate-to-high AIDS prevalence rates revealed strikingly similar rates of available housing. Similarly, the volume, range, and character of medical care available to indigent AIDS patients grew markedly in both demonstration and nondemonstration cities. Public clinics and hospitals made major investments to develop primary care clinics for HIV-positive patients, and existing home nursing agencies increasingly served AIDS patients. These efforts all improved access.

In summary, program sites did develop new services. However, this
process was mirrored in other cities with high AIDS prevalence, the majority of which received federal funds for this purpose. It is difficult to determine whether these investments in the care of people with HIV disease would have been made without this substantial outside funding support.

Implications for community service consortia. The AIDS Health Services Program is one of several initiatives that rely upon consortia of community agencies to ameliorate specific social problems such as chronic mental illness or homelessness. Precisely because agencies collaborating in these initiatives do not want to restructure their service programs, case management is often proposed as the “glue” that holds the diverse components of the service system together. Based on our experience, we discuss the feasibility of case management as an effective means of coordinating care for HIV-infected individuals as well as for other patient populations.

Like the elderly and other populations, people with HIV disease are heterogeneous in terms of their needs. While most older persons do not require case management, most functionally compromised frail elders do have long-term care needs. Similarly, people in the early stages of HIV disease are unlikely to have substantial need for services. Even with the onset of serious illness, needs fluctuate dramatically due to the vagaries of HIV disease. This complicates the case manager’s job of monitoring clients’ needs because unmet needs can arise suddenly, just as formal help may become superfluous as symptoms abate. This phenomenon is not unique to AIDS but is applicable to all chronic, progressive diseases for which both treatment and the disease itself can cause temporary loss of independence.

Case managers’ client caseload varies by type of client; some case managers can have from thirty to sixty long-term care clients. This requires case managers to frequently monitor problem flare-ups in a select, diverse population of “needy” individuals. Most agencies doing case management were initially reluctant to impose eligibility or “targeting” criteria for fear of alienating their constituencies. Nonetheless, establishing sensible criteria for making referrals to case management is essential for an efficient and equitable system, despite the difficulty in doing so. The best approach to establishing such criteria would involve input from providers as well as patient advocates, not just for AIDS but also for other chronic illnesses.

High-quality case management for chronically ill populations requires a balance between the social and the medical perspectives, given that the majority of patients’ time is spent in the community. Community-based case management cannot avoid interaction with and knowledge of the health care system. The more complex the client’s medical needs are, the more knowledgeable the case manager must be. Without medical knowledge, case managers are ineffective. On the other hand, hospital-based case management has a tendency to revert to discharge planning. Our data and
those of others studying the elderly suggest that hospital-based case managers have limited contact with the client in the community.\textsuperscript{16}

The authority of case managers was repeatedly called into question in the AIDS Health Services Program because they served as “brokers;” the only resource they had to offer the client or other agencies was their own time. Devoting attention to the individual case rather than planning and advocating for system change has been characteristic of most case management programs regardless of the population. As Carol Austin noted in her discussion of case management for frail elderly and mentally ill persons, “System change has been underdeveloped because most case managers cannot influence the distribution, type and supply of resources within their local delivery systems.”\textsuperscript{17} However, giving this type of authority to the case manager could result in a reallocation of resources among members of the consortia, which might compromise their continued survival.

In summary, the two conceptual pillars that the AIDS Health Services Program relied upon were interagency consortia and case management. We have seen that both are difficult to implement. In the future the considerable effort and talent necessary to build and maintain consortia and complex case management systems might be better devoted to more focused activities, such as forging bilateral partnerships between community-based service organizations and health clinics. These would eliminate the need for highly complex interagency collaboration networks without sacrificing the synergy that should derive from combined medical and social perspectives in caring for persons with chronic illness.

\textit{This work was supported by Robert Wood Johnson Foundation Grant no. 12044.}

\textbf{NOTES}


10. Ibid.


15. Austin and Applebaum, Long Term Care Case Management.

16. Ibid.