Empowering the Frail Elderly

Although economic necessity has been the primary force behind the search for alternatives to traditional nursing home care, providers experimenting with various care management and assisted living options have other, more compelling reasons for changing their approach to senior care.

At the annual meeting of the American Association of Homes for the Aging (AAHA) in Boston, presenters stressed the best reason for developing assisted living options is that such programs give the elderly more autonomy. But they warned that adopting truly client-centered, empowering approaches to care management and assisted living often entails overcoming powerful organizational and governmental barriers.

Northern European Assisted Living

One obstacle to developing effective assisted living projects in the United States is that eldercare programs have traditionally had to work under a "fear-based system of regulations," according to Victor Regnier. The regulatory environment discourages independence at all levels, Regnier said, forcing care givers to emphasize compliance over empowerment and reducing patients to passive recipients of service.

Last summer Regnier, who has a dual appointment at the School of Architecture and the Andrus Gerontology Center at the University of Southern California in Los Angeles, made site visits to 100 nursing homes and assisted living projects in Northern Europe. One of the most striking differences he found between U.S. and Northern European nursing homes was the level of integration with the surrounding community. "Even the most innovative American projects tend to be set off and self-enclosed," Regnier noted. In contrast, Northern European services and facilities maximize residents' contact with the community while preserving their privacy and autonomy.

For example, a residential facility in a Danish city was designed around a walking path between a hospital and a railroad depot. "The site provided an interesting, engaging place for people to sit and watch, or visit with one another," Regnier said. One Swedish assisted living center is located in the unused portion of a junior high school. Students and residents eat lunch together in the cafeteria and share the gym.

"The nurses station is the epitome of institutionalization in the United States. Off-limits for patients, it transforms nurses from care givers to record keepers," said Regnier.

Most of the European projects provide "mixed-use" services—available to clients and to area residents. Of the 100 assisted living centers Regnier visited, 80 had restaurants open to the public, and many provided home care and day care for older persons in the neighborhood. An assisted living center in Sweden offers home healthcare to clients and nearby residents, with nurses on bicycles answering calls.

European projects also foster a more relaxed, informal relationship between care givers and clients. The difference came home to Regnier when he visited a Danish nursing home and immediately felt that something was missing. He soon realized that the missing "something" was the nurses station. "The nurses station is the epitome of institutionalization in the United States," Regnier said. "It's the space for 'official business.' Off-limits for patients, it transforms nurses from care givers to record keepers the moment they enter."

In the place of a nurses station, Regnier found a small alcove with a desk, a chair, and two notebooks: one for entering doctors orders; the second notebook for nurses to record observations about patients, enter shift change communications, and even leave messages for patients. The patients were free to make entries as well, which ranged from reminders for nurses to refill a prescription needed to comments on food preparation to simple greetings. When Regnier asked the nurses whether reserving a space for record keeping might be more efficient, they responded that their job was to help people, and that they could not do that very well if they were separated from the patients.

The projects Regnier visited were invariably small scale, with few serving more than 50 clients.

GUIDELINES FOR ASSISTED LIVING

At the annual meeting of the American Association of Homes for the Aging, Victor Regnier presented the following guidelines for assisted living projects:

- Projects should have residential appearance (look like a house, not a hospital).
- They should be small scale—20 to 60 units (small enough to feel like a group; large enough for economies of scale).
- They should deal with the whole person as an individual, integrating assessment and treatment plans to meet the person's unique needs.
- They should involve the family as active partners in the care-giving process.
- They should focus on mental and physical stimulation to build on existing competencies and to rebuild lost ones.
- They should provide residential privacy.
- They should enable residents to maintain connections with the surrounding community.
- They should focus on fostering interdependence, independence, and individuality (emphasizing self-maintenance with assistance).
- They should provide services that help residents cope with frailties.

In a number of cases, providers had to reorganize existing larger facilities, built when a "bigger-is-better" philosophy was in effect, to adapt to new approaches to long-term care. "I found a lot of cases of decentralization," he said, "and all of them work."

A nursing home in Sweden provided an interesting example of the adaptation of an existing structure to different purposes. The structure of a 96-bed facility built in the 1970s was converted into six 16-bed units. Each ward was remodeled, and each is unique. Patients participate in staff meetings, which are held every 7 to 10 days, and they are actively involved in operational decisions. For example, each unit does its own hiring, and patients make up half of the hiring committee.

Shared Power and Responsibility

Such sharing of power and responsibility is basic to the European approach to assisted living. At all the sites Regnier visited, providers promoted self-maintenance, even for clients with relatively severe mental and physical impairments. In Sweden, Alzheimer's group homes are integrated into other assisted living projects and even into public family housing. Care plans emphasize activities of daily living (ADL) therapy, making clients responsible for routine chores such as setting the table, fixing meals, and doing laundry. In some programs, persons with Alzheimer's have fully equipped kitchens with specially designed safety devices, such as burners that can be operated only after the user pushes a series of buttons. "The stress is on finding simple, effective ways to adapt the environment to a person's disabilities without reducing the person to total dependence," Regnier said.

One difficulty U.S. providers face in designing and implementing care programs is a lack of social support, Regnier noted.

One difficulty U.S. providers face in designing and implementing innovative care programs is a lack of social support, Regnier noted. "The problem is not simply economic. It involves the perception that social work is part of a bureaucratic welfare system that saps resources and does more harm than good." The experience in Northern Europe is just the opposite. "Care givers are treated as professional, competent people, respected and supported in their work by the broad society," Regnier told the audience. "They know they have the community's trust and they are contributing to the social good."

Northern Europeans also agree that all persons, rich and poor, are entitled to housing and care that preserves their autonomy and privacy. Regnier, who has also studied innovative assisted living arrangements in the United States, said that of the best 100 U.S. programs, only 10 were for moderate- to low-income persons. In Europe, only 10 of the top 100 projects were for high-income individuals.

Regnier predicts that assisted living arrangements will gain increasing government support in the United States primarily because they promise to be less costly than nursing homes. But he says that unless organizations work to create a positive social and political environment, access to high-quality care and service will likely remain restricted to those who can afford it.

Assisted Living for Low-Income Elderly

In the United States, the lower cost of assisted living services is already beginning to attract for-profit providers. In an article for the *Wall Street Journal*, Michael J. McCarthy reports that Marriot Corporation has opened four 100-bed facilities and has plans for a national chain. McCarthy cites a Coopers & Lybrand study showing that nursing homes' operating expenses run at about 80 percent of their revenues, whereas assisted living facilities' expenses are only about 55 percent to 60 percent of their revenues ("Search for Alternatives to the Nursing Home Yields 'Assisted Living,'" December 4, 1992, pp. A1-A8).

But at an average cost of $1,763 a month, private assisted living remains beyond the means of

most elderly Americans. For low-income seniors who must depend on federal and state subsidies, access to assisted living programs is rarely an option.

Program Planning In the mid-1980s, St. Paul–area eldercare providers got together to consider alternatives for low-income seniors at risk for nursing home placement. Their goal was to find a way to work within existing state and federal funding structures for long-term care and housing to create an accessible program for poor seniors in the Twin Cities area.

In a session at the AAHA meeting, Jeanette Metz explained that the group considered what kinds of services low-income persons at risk for nursing home placement would need to be able to remain in the community. Metz—director of community-based and clinic services at the Wilder Foundation in St. Paul—said they concluded the minimum requirements would be 24-hour-a-day accessible support, an emergency on-site response system, laundry and housekeeping services, and meals.

With support from the state of Minnesota and the U.S. Department of Housing and Urban Development (HUD), the group got permission to set up an experimental assisted living project at Ravoux Hi-Rise, a HUD-sponsored congregate living project in St. Paul. Metz said the Wilder Foundation, which focuses on providing social services to the poor, was already furnishing congregate services and adult day care at Ravoux. "But we found that many residents needed more services in order to remain in their housing units."

Services Provided Under the arrangement, 36 of Ravoux's 272 units would be reserved for clients of an assisted living program administered by the Wilder Foundation's department of community-based and clinic services. In addition to the basic services (i.e., meals, emergency assistance, 24-hour on-site help, and laundry and light housekeeping), clients have access to the following optional services:

- Personal care assistance
- An activity program that provides opportunities for exercise, social contact, and special activities
- Assistance with or reminders to take oral medications
- Consultation with healthcare or therapy professionals when needed

To enter for the program, potential clients must meet state nursing home eligibility criteria and applicable HUD standards. In addition, clients must not wander, must be able to transfer independently, and must comply with program requirements.

Clients needed 24-hour accessible support, an emergency response system, laundry and housekeeping, and meals, Metz said.

Outcomes Study When the program was established, the state of Minnesota commissioned a study to determine its success in preserving patient autonomy. The study tracked changes in ADL dependence for 25 clients of the Ravoux program and a comparable group of residents at the Wilder Nursing Home in St. Paul over a one-year period. Clients were divided into five groups according to their level of ADL dependence.

As the **Table** shows, most Ravoux residents either maintained the same level of ADL dependence or improved. Members of the comparison group, on the other hand, showed a dramatic

ASSISTED LIVING AND NURSING HOMES: COMPARISON OF OUTCOMES*

ADL Dependence	Ravoux Assisted Living		Wilder Nursing Home	
	On Admission	After 12 Months	On Admission	After 12 Months
None	12%	16%	12%	0%
Very low	16	20	24	8
Low	68	52	60	52
Medium	4	12	4	4
High	0	0	0	36

*Based on a comparison of activities of daily living status of 25 clients of Ravoux Assisted Living and 25 clients of Wilder Nursing Home, St. Paul.

ORGANIZATIONAL CHECKLIST

To get a perspective on the values that drive their organization, care givers can rank each of the following items based on the priority they think administration and management give it:

- Turf protection
- Minimizing costs
- Complying with funding and third-party requirements
- Increasing the number of older persons served
- Improving patient service based on worker and client input
- Advocating for changes in the service delivery system
- Developing new programs to improve financial status
- Increasing consumer choice and satisfaction
- Helping older persons remain in the least restrictive environment

increase in their need for assistance with routine daily activities. The total cost of care for Ravoux clients was one-third lower than it was for nursing home residents, averaging between $900 and $1,000 a month. State and county governments reimburse clients for most of the costs.

The Wilder Foundation added two more assisted living programs for low-income seniors in the late 1980s. Of the 36 units available at each of the facilities, about 30 are usually occupied.

Concerns for the Future Despite the program's success, Jocelyn Berdan, alternative living coordinator at the Wilder Foundation, expressed some concerns about its future. One potential source of trouble is a new set of home care regulations being considered by the Minnesota state legislature. The regulations would require licensure of home health aides, which would add a cost that the program may not be able to bear. "No other organization in the state runs the type of program we have, and so we tend to be subject to regulations that weren't really intended for us," Berdan said.

She added that the state has tried to be flexible and helpful, and in most cases its regulations are much less restrictive than they were five years ago. But the project is still reimbursed at only 42 percent of the rate paid to nursing homes.

Wilder and other local agencies have initiated collaborative efforts to lobby the state legislature for increased funding and less-restrictive regulations for assisted living projects. One goal is to change state oversight of assisted living from the Minnesota Department of Health to the Department of Human Services, which would ease the regulatory burden somewhat. Another is to gain access to certain federal funds that are currently unavailable without a waiver.

Berdan said state licensing requirements might add costs the program could not bear.

EMPOWERMENT GERIATRIC CARE MODEL

Although legislative advocacy is crucial to support expanded living choices for seniors, professionals who work closely with the frail elderly know that advocacy sometimes entails working for change within one's own organization.

Mixed Messages One problem care managers face is that messages their organizations send them—cut costs and promote consumers' interests—often conflict, Mary Carmel Ruffolo told the audience. Ruffolo, who is on the faculty of the School of Social Work at Syracuse University, said organizations sometimes pursue programs for the wrong reasons. "Care management programs are very popular because people see them as a conservative response to changing the system," she noted.

Ruffolo said that care managers who want to encourage consumer choice and independence often find that the system within which they work frustrates their progress instead of facilitating it. "When you commit to an empowerment geriatric care model," she said, "you're also committing to changing dysfunctional systems—things that are not working for large groups of people, as well as actions or philosophies that are not working for individuals within your community."

Ruffolo suggested that care givers fill out a checklist giving their perception of the program's administrative and managerial priorities (see **Box**). Even when their stated mission suggests otherwise, organizations that emphasize such factors as complying with third-party funding requirements, improving financial status, or increasing referrals remain locked into a "funding-stream, provider-driven model," she said. Ranking an organization's priorities is a quick way to check whether its practice conforms with its stated objectives.

Organizational Commitment Changing to a consumer-oriented empowerment model requires commitment at all levels of the organization. Ruffolo stressed that care managers must learn to identify and draw out abilities their clients may not be aware they possess. They must also be prepared to become advocates for their clients when organizational interests and customers' interest are at odds. Ruffolo noted that such conflicts are most likely to be the result of budgetary pressures.

An empowerment geriatric care approach provides a different slant on the frail elderly's vulnerabilities, Ruffolo said. Although care managers must be aware of the obvious problems caused by illness, disability, or impairment, they should realize that these conditions also put the

client's autonomy at risk. "Because older persons no longer have all the resources they once had, others may want to come in and make decisions for them. As advocates for our clients, one thing we have to fight is this paternalistic view of caring."

Professional paternalism is also a threat to the frail elderly, Ruffolo said. "It's easy to fall into the trap of wanting to be the helper and losing focus of what's in the older person's best interests and what that person wants," Ruffolo warned. Organizational inertia can block clients' access to appropriate levels of care as well. "It's very hard to move people from one level of care to another unless you have the whole system working for that."

Forms of Autonomy In developing a care plan that empowers clients, care managers must differentiate between those areas of life over which persons must give up control and those which persons can still manage.

"People don't lose their autonomy all of a sudden," Ruffolo said. "It's a process. To support clients in the abilities they still possess, care managers need a method for identifying different kinds of autonomy." She defined types of autonomy as follows:

- *Decisional versus executional.* Ruffolo noted that certain frail elderly persons may not be able to dress themselves, but they can still decide what they want to wear. In such a case, Ruffolo said, the person no longer possesses "executional" autonomy, but his or her "decisional" autonomy remains intact.
- *Direct versus delegated.* "Most frail elderly can still make important decisions about their life, such as where they want to live," Ruffolo said. "But they may need help in certain areas, such as managing financial assets."
- *Competent versus incapacitated.* One trap care managers can fall into is to make judgments about persons' competence when their decisions seem incorrect. "When what clients want doesn't fit what we want, we can easily start thinking about them as incapacitated," Ruffolo warned. "But more often than not, the real problem is that they are using a different frame than we are. Few people actually get to the point of being incapacitated, and when they do, it is often because their real abilities have been denied or unappreciated."
- *Immediate versus long range.* Family members often want to make decisions to ensure an elderly person's long-term security, but the person may resist attempts to take immediate action. "It may be appropriate to make plans for the future," Ruffolo said, "but families should also respect a person's wish to continue to get along alone."

"To support clients in the abilities they still possess, care managers need a method for identifying different kinds of autonomy," explained Ruffolo.

Care Manager Functions

Identifying strengths and ensuring that clients have appropriate support are the two key functions of the care manager, Ruffolo said. She noted that assessment models have traditionally emphasized clients' losses and impairments. "If we used such models to analyze our own status and environment, most of us would look like good candidates for institutionalization."

A comprehensive service plan should consider areas in which clients can strengthen their ability to care for themselves and areas in which they can benefit from professional help. In developing the plan, the care manager should also look for "mutual care" opportunities, Ruffolo said.

"Using the empowerment model, you will find that a 'mutual care network'—neighbors, friends, and others in the environment who are in daily contact with the client—is often the most important element in a care plan," Ruffolo said. Because care managers spend much of their time developing links to professional care services, they often miss this vital source of support.

Ruffolo identified four care manager roles:

- *Partner in the planning process.* Under an empowerment model, the care manager becomes less an expert and more a "co-producer," Ruffolo noted. "You may know the resources and the standards of care," she said, "but you also have to recognize that you don't have the whole picture." She added that involving clients in constructing their own care plans can help them build self-care skills.
- *Broker.* Being a service broker for the client is a role professionals play under all care management models.
- *Relationship builder.* "In all types of empowerment models," Ruffolo said, "you concentrate on building relationships." In a long-term care facility, the care manager will help build relationships between the client and other residents and between the client and care givers. In other cases, the care manager might focus on strengthening and redefining family relationships.
- *Advocate.* Advocacy may be the most important role the care manager plays, Ruffolo concluded. "It may be as simple as ensuring that care givers come at the times they are supposed to be coming," she said. But at a higher level, advocacy focuses "on expanding the system to respond to the variety of needs people have."

—Phil Rheinecker