

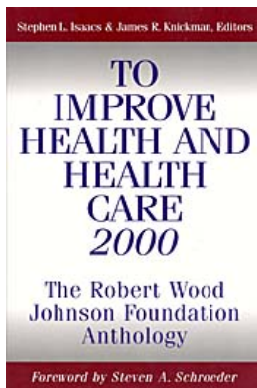
# Adult Day Centers

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## *Editor's Introduction*

One of the Foundation's priorities is to help communities improve their capacity to deliver services to chronically ill people, including those with Alzheimer's disease and the frail elderly. The Foundation's strategy is to promote the use of both formal services and, perhaps more important, informal services provided by families and friends.

Adult day care, the topic of this chapter, provides formal services that do not supplant informal services. Instead the services provided by adult day centers allow chronically ill people to continue living at home. The centers help informal caregivers by providing services during work hours, when many family members are not able to look after their loved ones.

Since 1987, the Foundation has supported a series of programs to test the usefulness of adult day care and then to promote its replication. This chapter presents a history of the three distinct investments made by the Foundation on this topic. In many ways, this cycle represents the archetype of the Foundation's approach to grantmaking: a Phase I program—in this case *the Dementia Care and Respite Services Program*—runs a demonstration to test a new idea. A Phase II program—*Partners in Caregiving: The Dementia Services Program*—expands the program to other locations. And a Phase III program offers technical assistance and guidance to an even wider set of communities.

The chapter was written by Rona Smyth Henry, Nancy Cox, Burton Reifler and Carolyn Asbury, the team that designed and assisted the adult day centers programs discussed in the following pages. In addition to examining the programs, the authors offer very practical guidance for communities interested in establishing or improving adult day centers.

Of course, adult day care represents just one facet of a well-functioning community care system for the chronically ill. Other Foundation efforts to increase and improve services available to chronically ill people have been described elsewhere in the *Anthology* series: the Springfield, Mass. study that gathered information about the services available to chronically ill persons (1997 *Anthology*); the Faith in Action program that spurred the formation of religious coalitions to match volunteers with older Americans in need (1998–1999 *Anthology*); the Chronic Care Initiatives in HMOs and the Building Health Systems for People with Chronic Illness program (1998–1999 *Anthology*); and the Mental Health Services Program for Youth (1998–1999 *Anthology*).

Caregivers who cope with the problems affecting a loved one suffering from dementia confront a process that can span twenty years or more. According to the national Alzheimer's Association, dementia is the loss of intellectual abilities—thinking, remembering and reasoning—to such a severe degree that it interferes with a person's ability to function on a daily basis. It is not a disease itself but a group of symptoms that accompany certain diseases. Some of the well-known specific forms are Alzheimer's disease, vascular dementia, Huntington's disease, Pick's disease and Parkinson's disease. The most common dementing illness is Alzheimer's disease. Affecting four million adults in the United States,<sup>1</sup> Alzheimer's progressively destroys one's memory, judgment and ability to communicate, often with profound changes in personality, mood and behavior. Eventually, individuals are unable to care for themselves.

Not until Alzheimer's produces altered sleep patterns, incontinence, combativeness, wandering and severe mental impairment do some caregivers turn to a nursing home or another institution for relief. Often, community-based services are lacking, and even when they are available, caregivers may have difficulty piecing together the information about desired services and then making the appropriate arrangements—especially because there are few central information sources or referral sources in place. For many caregivers who have a loved one with dementia, nursing homes are not necessarily the best option. The expense is often too great, and patients are ineligible for Medicaid unless their assets are nearly exhausted.

Since most people who suffer from a chronic, debilitating illness prefer to remain in their own home or in the home of a family member or friend, adult day centers offer an attractive alternative to nursing homes. Such centers are community-based group programs that provide health, social and support services for adults with decreased physical, mental and social functioning. These adults may have Alzheimer's disease or other dementing illnesses, mental retardation or other developmental disabilities, or chronic mental illness; they may also be mentally alert but have physical problems. They are in need of supervision—for managing their medication, say, or to keep them from wandering. They may also require social interaction and assistance with the activities of daily living such as eating, walking, toileting, bathing, and dressing.

An adult day center provides a structured, comprehensive program in a protective setting. Participants go in the morning and come home at the end of the day. Besides providing a therapeutic environment for

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the person in need of care, a day center offers the family relief from the burden of caregiving. It lets caregivers who work continue to care for a loved one at home and provides a much-needed break for the nonworking caregiver.

Despite their obvious advantages, adult day centers are underutilized for two reasons: a lack of awareness on the part of caregivers and resistance to using the service. The resistance stems from several concerns, including guilt over needing help to care for a loved one; worry that the staff at a center will not extend the same compassionate care as family members, or that the staff will not be trained to deal with the behavior of their loved one; fear that a family member who is mildly impaired may become depressed at seeing severely impaired individuals; fear that caregivers will be told they are doing things wrong at home; denial that a problem exists or that they need help, because this would mean confronting the serious long-term effects of the disease; and concern that financial resources will be depleted before nursing home care is needed.

Some of these concerns were once valid, notably in the 1980s, when the Robert Wood Johnson Foundation was considering funding in this area. At that time, adult day centers were not well-equipped to serve people with dementia, and many centers excluded those who had symptoms such as wandering and incontinence. In 1984, only about 20 out of 800 day centers in the United States specialized in dementia care,<sup>2</sup> and a 1986 report revealed that only 20 percent of the day centers had participants with any cognitive impairment.<sup>3</sup>

The adult day centers that specialized in helping people with dementia used specific techniques to meet the needs of those who had cognitive impairments—supervised wandering areas, for example, and timed bathroom breaks to deal with incontinence. To involve everyone in a supervised but supportive environment, these centers offered activities such as reminiscing, music and art. They generally had a small enrollment, a low staff-to-participant ratio to allow for close supervision and a heavy reliance on charitable funds to support their programs.<sup>4</sup>

Financing for such services was fragmented, and continues to be so. Adult day centers must piece together federal, state and local funds from sources such as Medicaid, social service block grants, the Older Americans Act, local Veterans Affairs (VA) medical centers, Medicare dollars (not for adult day services but for rehabilitative efforts such as physical or speech therapy), the Department of Agriculture's food reimbursement program, state general fund dollars and philanthropies. Adult day centers cannot,

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however, receive funds from Medicaid, Medicare and the VA if medical services are not provided. Furthermore, even if medical services are provided, Medicaid and VA funds are not available in all states. Increasingly, private insurance policies are covering home-based and community-based care, but insurance remains an extremely small source of revenues. Adult day centers must also rely on fees from participants and their families to cover the cost of operations.

#### THE DEMENTIA CARE AND RESPITE SERVICES PROGRAM

In 1987, to address the need for community-based, nonresidential programs to meet the needs of demented individuals and their caregivers, the Robert Wood Johnson Foundation created the Dementia Care and Respite Services Program. With a \$3.9-million commitment from the Foundation and \$625,000 each from the national Alzheimer's Association and the federal Administration on Aging, this program, which ran from 1988 to 1992, was the first national adult day services demonstration program. Technical assistance and direction were provided by a national program office at the Wake Forest University School of Medicine, under the direction of Burton Reifler. The Dementia Care and Respite Services Program had three main goals: first, to expand the availability of dementia-specific day programs, other community and in-home respite services, and related health and support services; second, to demonstrate that specialized day centers could provide services needed to deal with a wide range of disease severity; and third, to determine whether the centers could become financially viable, especially by focusing on the private pay market.

Adult day centers that were public entities or nonprofit organizations were eligible for grants of up to \$300,000. Out of 283 applications, 19 sites were selected for a grant award, with 17 grantees (representing 21 organizations and operating a total of 24 adult day centers in 13 states) participating over the entire program. The average award totaled \$281,000 over four years. Foundation support was set up as deficit financing rather than fixed annual awards; that is, grantees received funds as needed to cover their deficits. Grantees used funds to expand their hours, and also to improve or add dementia care to their programs. (The program sites and their characteristics are found in Exhibits 5.1 and 5.2.)

The program had goals that were relatively easy to measure, involving utilization and financial performance. Enrollment, average daily attendance and satisfaction surveys were used to determine whether the day centers were meeting the needs of caregivers. By the third year of the program, its goals were being met. Participants and their families were responding well to the various innovative programs such as music and art therapy, drop-in respite, and weekend and overnight respite care. As noted by program evaluators, operational choices made by day centers—such as being open longer hours and providing transportation—

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contributed to caregiver satisfaction.<sup>5</sup> The data revealed that the centers were becoming financially viable and were relying less on grants and contributions and more on operating revenue (government reimbursement for services and fees paid by participants or their families). The program showed that caregivers valued the service enough to pay for it: the sites in the program increased their private pay revenues by an average of 170 percent, and some centers were able to cover all their expenses from private payers alone. By the end of the program, the 17 sites were meeting 64 percent of their cash expenses through net operating revenues. In sum the program showed that adult day centers could effectively care for people with Alzheimer's disease, provide support to their caregivers and do so in a financially viable manner.

#### PARTNERS IN CAREGIVING: THE DEMENTIA SERVICES PROGRAM

In 1992, to build on the progress of the Dementia Care and Respite Services Program and to promote further service innovation, the Robert Wood Johnson Foundation created Partners in Caregiving: The Dementia Services Program. This \$2.5-million program, also under the direction of the Wake Forest University School of Medicine, was designed to determine whether the lessons from the demonstration program could be applied to a new group of sites more quickly and economically and with similar success.

Partners in Caregiving was larger in scope, with 50 participating sites (in 30 states and the District of Columbia) selected from 384 applicants. It did not just replicate the Dementia Care and Respite Services Program on a national scale. It tested a number of ideas concerning services to people with chronic disabilities.

For instance, the Foundation wanted to find out whether the adult day center model could be appropriate for people with other chronic disabling conditions. So despite terming it "The Dementia Services Program," the new program provided services for people with conditions other than dementia. To test whether programs could operate under different financial conditions, the Foundation gave smaller grants (up to \$100,000 for expansion sites and up to \$250,000 for start-up centers) for shorter periods (two or three years). To encourage sustainability, each \$2 of Foundation funds had to be matched by \$1 in local funds. (Partners in Caregiving sites and their characteristics are found in Exhibits 5.3 and 5.4.)

The Foundation also varied the kind of assistance it provided. All applicants applied for a grant, but only half of the 50 participating sites received funds, which included limited technical assistance (site visits and

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annual program meetings); the other half received intensive technical assistance, which included special training workshops and resource materials, consultant services, visits to model day centers, access to a toll-free help line at the national program office, and hands-on assistance from an assigned mentor—a project director from the Dementia Care and Respite Services Program—in addition to site visits and annual program meetings. Centers receiving grant support averaged \$93,000 a site plus an average cost to the national program office of \$13,500 for basic technical assistance to the grant-funded sites. The average cost for the sites receiving technical assistance only was \$39,000.

In Partners in Caregiving, many different service models were developed. Some centers served a variety of people such as the cognitively impaired and the physically challenged in separate programs under one roof. Others integrated people with different conditions—such as persons with Alzheimer's disease or other dementing illnesses, mental retardation, chronic mental illness, and the frail elderly—into one program. Some centers served a single population, such as those with early-stage Alzheimer's or individuals with multiple sclerosis.

There was great variety among the settings for the centers. Some were housed in nursing homes, hospitals and mental health facilities, and others were freestanding. Some adult day centers served more than 80 people a day; others chose not to exceed 15 to 20 a day. Further differences took shape around the services offered by centers and facility design.

Improvements in revenue-gathering and financial performance were gratifying. At the end of the Partners in Caregiving Program, sites, on average, were meeting 83 percent of their cash expenses through net operating revenue.<sup>6</sup>

The Dementia Care and Respite Services Program and Partners in Caregiving produced data on service utilization and financial performance of adult day centers; they also show the gains that can be made through attention to marketing and financial management. The two programs offer many lessons about how adult day centers can be more responsive to the needs of participants and their caregivers, and about how these programs can become financially viable.

#### 1. Solve the Customer's Problem

Recruiting day center participants and then retaining them were the two biggest challenges, and the most

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successful centers were those that showed a willingness to adapt to fit the needs and wants of individual participants and their families, and that were able to find creative solutions to problems:

*Shelby, N.C.*

Individuals with dementia who exhibit behavior problems such as agitation, combativeness and wandering are not accepted by many day centers. In one instance at the Life Enrichment Center, a nurse worked almost daily with the physician of a new participant to regulate a new medication that controlled the patient's behavior sufficiently for him to attend the day center.

*Logan, Utah*

For some people, a hearing impairment is what limits their involvement in activities. The Sunshine Terrace Adult Day Center bought a small public address system to use for all guest speakers, staff announcements and group activities. It helped certain dementia clients hear better, thus engaging them in the program and reducing wandering and other behavior problems.

*Everett, Mass.*

Transportation can be a major problem for families. To accommodate a caregiver who had to be at work before the van could pick up her mother at home, the Community Family arranged pickup at a mall parking lot close to where the van route started.

Responsive centers also showed a willingness to expand their services to address the needs and wants of participants and caregivers:

*Fairfax, Va.*

Families caring for those with dementia often have problems getting them up and out in the morning or getting them ready for bed at night. A consortium of the Family Respite Center in Falls Church, Va., and the Fairfax County Health Department developed an "up and tuck" service, sending a worker into the home for up to two hours in the morning and two hours in the evening to help address these problems.

*Warwick, R.I.*

Central Adult Daycare Services, Inc., began opening on Saturday so that working caregivers could have some time alone to unwind, go shopping, or visit with family or

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friends. This innovation proved to be so successful that Saturday became a regular day of service.

*Salem, Va.*

The Adult Care Center of Roanoke Valley offered overnight respites—Friday, Saturday and Sunday nights—to allow caregivers an occasional free weekend and a week-long respite in July to allow caregiver vacations.

## 2. Stay Open a Full Day

At the beginning of the first program, it was typical for adult day centers to be open only from 10 a.m. to 3 p.m., and in some places only two or three days a week. The hours were often dictated by the availability of funds, but sometimes the hours were short to allow time for staff to transport participants to and from the center. A short day made it impossible for working caregivers to use the program, however, thus cutting out a market segment that often had the ability to pay in full.

A longer day of programming is appealing to nonworking caregivers, particularly retired spouses, who find it difficult to get themselves and their loved one up and ready to go early in the morning. Longer hours allow a participant to arrive later and stay later.

As a result, some centers adopted policies of remaining open longer. The Granat Alzheimer Respite Center in New Hyde Park, N.Y., the first Dementia Care and Respite Services Program start-up center to become financially self-sufficient, was open 12 hours a day (7 a.m.–7 p.m.), seven days per week. But even at this, the staff was still flexible, sometimes opening at 5 a.m. to accommodate a caregiver who worked an early shift.

At the end of the Dementia Care and Respite Services Program, a center's being open from 7 a.m. or 7:30 in the morning to 6 a.m. in the evening Monday through Friday was shown to be a predictor of financial success.<sup>7</sup> Centers with these minimum hours met 84 percent of their expenses, on average, through net operating revenue. Centers with shorter hours achieved an average of only 57 percent.

## 3. Give Everyone the Opportunity to Pay

Even before the demonstration program started, most centers were tapping into any government funding available, but they had not realized the full potential of participant fees. Centers almost always charged less than the cost of providing their services, and in many cases they did not even know what their unit cost was. They were usually run by directors with nursing or social work backgrounds who sometimes



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lacked the business skills needed to address pricing issues. Directors, their staff and their board were often reluctant to charge the full cost of care, for fear that some people would be unable to afford the service.

Because the Dementia Care and Respite Services Program sought to test whether families would be willing to pay for services, centers were encouraged to calculate their full cost of care and to begin charging it—offering discounts to those in need. They were also encouraged to identify funds to make up for the discounts (training in basic fundraising was provided to the sites) and to keep the discounts within the overall budget. These strategies helped increase private pay revenues substantially, and participants rarely dropped out of the program as a result of price increases. The strategies also led to greater financial stability.

*St. Louis, Mo.*

By the third year of operation, St. Elizabeth Adult Day Care Center was operating at a surplus without grant support; 60 percent of its operating revenue came from private-pay fees and 40 percent from government reimbursement.

*Middlebury, Vt.*

Elderly Services watched its monthly revenue from participant fees increase by more than 50 percent in a two-year period when it abandoned a sliding-scale fee structure in favor of set fees with discounts available.

Other pricing strategies included the following:

- Pricing for days of service reserved rather than for those used. This strategy, almost universal for child care programs, helped pay for staff members whose work schedule had been based on participant enrollment; it also had a side benefit—improving overall attendance. Many centers found that their daily attendance and cash flow increased when they went to a prepayment system. Centers also became more sophisticated in their booking policies. Over time, they learned what a typical no-show rate would be and overbooked accordingly.
- Allowing participants to attend for part of a day—half-days, and even hourly—and setting fees accordingly.
- Unbundling ancillary services from the daily program fee and charging separately for these services. For example, many centers allowed people to buy transportation, bathing, nail care or meals as extra services—the choice being based on the needs and preferences of the participants.

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- Offering package deals: some centers bundled individual services into packages and offered them at special rates that were less than the same services priced separately.

#### 4. Provide or Arrange Transportation

Transportation is costly, but it's a vital part of any program. Everyone may not need a ride, but many are not able to attend an adult day center without one. Many programs noted higher attendance when transportation was offered. Providing or arranging for transportation also was associated with better financial performance.<sup>8</sup>

##### *Bloomington, Minn.*

When Martin Luther Manor Adult Day Services opened, it had no way to transport participants. Not much growth in enrollment was seen until the center rented a van and began to provide transportation. Eventually, a full-fledged transportation program evolved, with four vans, seven part-time drivers and a transportation coordinator, and enrollment continued to increase.

##### *Middlebury, Vermont*

The in-house transportation program of Elderly Services is not just door to door but "through the door," with van drivers providing personal care services in the home. And, for added revenue, the vans and drivers are available for hire by the community.

#### 5. Offer a Full Day of Engaging Activities

Because people attending day centers have varied backgrounds, preferences, and abilities, a center must offer a variety of activities. Activities tend to be engaging when they focus on the abilities, not the disabilities, of the participant and on both old and new skills. Engaging activities are therapeutic in nature and attend to emotional and intellectual needs as well as physical ones.

##### *Logan, Utah*

The Sunshine Terrace Adult Day Center created a music therapy program, enabling people with dementia, who had not played a musical instrument in years, to rediscover their talent. They also awakened musical interest in those who had never shown it before.

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*Kona, Hawaii*

The Kona Adult Day Center used art therapy to help participants express their feelings and achieve a sense of accomplishment. Participants learned how to make silk paper greeting cards, and the center began selling these to raise money.

Some day centers operate a program of parallel activities or track programming, providing options for participants that fit their interests and abilities. Three or four activities, such as art, gardening, cooking, and exercise, may be going on simultaneously.

Many day centers stay connected with the community by having the participants go out or having members of the community come to them:

*Sioux Falls, S.D.*

The Center for Active Generations offers an hour-long, warm-water exercise program using the facilities at the local YWCA. As it is not far from the center, staff and participants walk there—two activities in one.

*Rome, Ga.*

Instead of participants going to a local health fair, Mercy Senior Care had such a fair at its own day center. Local health professionals volunteered their services, with over a hundred community residents stopping by to visit and have blood pressure and cholesterol checked.

6. Provide a Continuum of Care

People served by adult day centers often have many other needs. Those who live alone or with families having limited time to assist them may need in-home care for bathing, dressing, or household chores. Participants often have health problems that necessitate the coordination of medical services. And when the time comes, assistance may be needed with placement in a nursing home.

Adult day centers can serve as the nexus between acute care and long-term care. They often take a holistic approach to the care needs of participants, including the provision of support services for caregivers. In this way they provide a critical care management function.

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To help ensure that the needs and wants of both participants and caregivers are being met, adult day centers should provide either a continuum of care—using a one-stop shopping approach—or create partnerships with other community service providers:

*Wheat Ridge, Colo.*

Seniors' Resource Center takes a wide-ranging approach to accommodating all the needs of its rural participants. In addition to Day Break (its adult day center), it has a network of support services that include short-term overnight care, in-home personal care and homemaker assistance, and finding part-time jobs for caregivers. It also provides information and referral, outreach and case management, nutrition, social, recreational and educational programs.

*Rochester, N.Y.*

The MS Achievement Center at the Park serves people with multiple sclerosis (MS). By collaborating with the local MS chapter, a transportation company, and a variety of community resources such as psychiatric services, it is able to meet the needs of participants and thus enable them to avoid nursing home placement.

7. Recruit and Maintain Quality Staff

Quality care can exist only with quality staff. It is the staff that initially sells the program and then becomes a crucial element in the participant's and caregiver's choice to stay or go elsewhere.

Proper orientation and initial training, plus continuing individual and group education, are key components in developing a staff that can create a high-quality program, which, in turn, will attract a high-quality staff.

*Syracuse, N.Y.*

To attract and retain staff members, the Kirkpatrick Center of the Central New York Chapter of the Alzheimer's Association created a career ladder. The ladder establishes clear advancement steps: from program assistant to assistant team leader, to team leader, to community liaison, to site coordinator. Financial incentives are also provided for people coming in on the bottom rung and starting out at the minimum wage. They are given the opportunity to move to salaried positions, which can more than double their earnings.

*Lexington, Ky.*

The experiences of Helping Hand are captured in the book *The Best Friends Approach to Alzheimer's Care*.<sup>9</sup> Staff members at this dementia-specific day center have "the knack." The elements of the knack that are central to the Best Friends model of care include being well informed, having empathy, respecting basic rights, maintaining caregiving integrity, employing finesse, maintaining optimism, using humor, maintaining patience, developing flexibility, being nonjudgmental and valuing the moment.

*Seattle, Wash.*

Operating on the belief that all employees are creative and capable of making an improvement, ElderHealth Northwest created Paradigm Busters, an employee-run program with complete authority to recommend, implement, monitor and evaluate change. One positive change was a revamped nutrition service, so that meals are low-fat, low-salt, nutritionally sound, culturally diverse and pleasing to the palate. Overall, the program eases the tension that often arises with change, and builds common bonds within a diverse staff.

8. Help Caregivers Cope

A study by the national program office of participants in the Dementia Care and Respite Services Program found that most needed help with bathing (82%), dressing (76%) and grooming (73%), with just over half needing help with toileting.<sup>10</sup> Participants also averaged nine behavior problems, such as difficulty concentrating on a task, lack of initiative, inability to be left alone and losing or misplacing things. The level of disability among participants clearly showed that caregivers need support services.

Because caring for the frail elderly and those with dementia can be an overwhelming responsibility—one that can take 24 hours a day, seven days a week—additional support, even at added cost, is a welcome relief. The most popular support services are assisting caregivers in bathing, hair care and nail care—personal care activities that must be done by the caregiver with, on many occasions, an uncooperative loved one. Support groups and educational workshops are also important.

*Shelby, N.C.*

To meet the need of families for in-home care in the evenings and on weekends, the Life Enrichment Center developed a 43-hour training program for high school students and a 63-hour program for community college students, dovetailing with an existing nurses aide training program. Once students are trained and certified, they are

placed on a registry, referrals are made to families, and the students work as independent contractors.

*Madison, Wis.*

To provide a safe place for people in the early stage of Alzheimer's to express their feelings and learn how to cope with the disease, the Madison Area Adult Day Centers created a support group. A parallel support group was created for the caregivers and other family members, which served as a safe place to express feelings of fear and anger.

*North Miami Beach, Fla.*

Because of everyday responsibilities, caregivers usually have no time or energy to think about innovative activities for their loved one at home. To address this issue, the Gumenick Alzheimer's Center created what it called the B.A.G.—for "Be Active With Games." With twenty different activities in a canvas bag, the B.A.G. takes the guesswork out of coming up with enjoyable and appropriate activities.

#### 9. Market to Caregivers and Formal Referral Sources

Because adult day centers are not well known, marketing is a major challenge. Working with a marketing expert and center directors, program staff members developed a description of major caregiver market segments: Information Seekers, Respite Seekers and Care Seekers.<sup>11</sup> These market segments are broad categories that help centers decide whom they want to serve and how to design their services.

*Information Seekers* typically are caring for someone in the early stage of Alzheimer's disease. They are often in denial about the diagnosis, or deny that they need help. This group typically needs information about future service options as well as support in dealing with the psychological aspects of caregiving. Rather than trying to get this group to enroll a loved one in a day center, a center can use its time more efficiently by offering support groups and caregiver education. Because information seekers are potential users of services, staying in touch with them is important, so that when they are ready, they will think of the day center.

*Respite Seekers* want part-time care. They need occasional time out from caregiving, but do not want daily day center service. This segment has two subgroups: Givers, who want to provide all the care but are no longer physically or emotionally able to do so, and Responsibles, who provide care out of a sense of duty but who may not enjoy caregiving tasks.

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*Care Seekers* want all the help they can get and are ready for full-time day center services. They also have two subgroups: Delegators want their caregiving problem fixed, and may buy the first service available, whereas Balancers, because of other responsibilities, would like to provide the care themselves but cannot. They are very particular about the kind of care they buy, and will remain closely involved.

By understanding these market segments, centers can learn how to tailor their marketing messages to specific audiences and design programs that better meet the needs of participants and caregivers. This understanding, in turn, can lead to increased recruitment and to keeping participants enrolled at the centers.

Another marketing lesson is that formal referral sources, including health care professionals such as physicians and hospital discharge planners, social service agencies and other community service providers, and employers, account for 75 percent of referrals to day centers. These formal referrals come from organizations and individuals in the caregiver's institutional and service network. They are influenced strongly by personal relationships, contractual arrangements, targeted direct mail, one-on-one visits and repetitive contact (at least seven times per year per referral). Often, someone making a referral will get in touch with the day center directly on behalf of the caregiver. Of particular note is that formal referral sources account for up to two-thirds of actual day center enrollments. Only one-third of enrollments come from direct inquiries—caregivers and informal referral sources.

#### 10. Develop a Working Board of Directors

Members of the board of directors are ambassadors in the community, lending legitimacy and respect to the organization. Because the board is ultimately responsible for the organization, including its financial resources, it should not delegate the responsibility for raising funds to anyone else—not to a foundation, not to an outside consultant not to staff.

Since motivation and active participation go hand in hand, there is no substitute for leadership. The chairman of the board and the executive director of the organization have the major tasks of developing and motivating a working board with the goal not only of overseeing the program but also of actively participating in its development.

#### THE NEXT STEP: DISSEMINATING THE LESSONS

Since 1988, the national program office at the Wake Forest University School of Medicine has been documenting the lessons learned, best practices, and grassroots successes of the Dementia Care and

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Respite Services Program and Partners in Caregiving. The next step—a large-scale, national information program to reach adult day centers across the country that have not been participating sites in the two previous programs—was approved by the Foundation in 1998.

Through additional funding provided to the Partners in Caregiving Program, this two-and-a-half-year national initiative (1998–2001) will take the 10 years of lessons learned from the two earlier programs and disseminate the knowledge as widely as possible through the following:

- Mobile adult day services colleges: intensive three-day training sessions in 14 states, with videoconferencing to an additional nine states.
- Teaching day centers: a network of teaching centers to offer experiential training at national model adult day centers across the country.
- A toll-free hotline: a telephone assistance hotline to aid potential or existing adult day centers with program design, marketing and financial issues.
- A Web site: for information sharing and interactive questions and answers.
- A national publication: to keep centers up-to-date on cutting-edge developments in the field.
- National presentations: to encourage more interest in start-up ventures.

#### CONCLUSION

Where does dementia care stand today? Besides the four million people afflicted with Alzheimer's disease, 19 million caregivers are affected. It is estimated that by the year 2050 there will be 14 million people with dementia, over three times the number today.<sup>12</sup> At the same time, the pool of potential caregivers will shrink. In 1990, there were eleven people age fifty to sixty-four for every person over age 85. By 2050 this ratio will decrease to 4 to 1. Clearly, more support services will be needed.<sup>13</sup>

When the Foundation started in the field of adult day services, there were only about 1,000 adult day centers nationwide. Today there are perhaps 4,000. But the need is much greater. In 1993, with one center for every 20,000 people, it was determined that ten thousand day centers would be needed by the year 2000.<sup>14</sup>

The Dementia Care and Respite Services Program showed that adult day centers could serve people with dementia and be the locus of care by arranging or providing other needed respite and personal care services. It also showed that a demand for these services existed, and that people were willing to pay for them out-of-pocket.

According to the national program office, the Partners in Caregiving Program showed that technical



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assistance could be just as valuable as grant funding when trying to replicate models of care and that adult day centers can effectively serve people with other chronic conditions—mental retardation or developmental disabilities, mental illness, multiple sclerosis—and be financially viable at the same time.

Neither program, however, concentrated on reaching the most difficult-to-serve people. For example, only a few projects served rural and economically disadvantaged areas. The next challenge is to demonstrate how the delivery of services can grow and flourish in hard-to-serve areas. Expanding adult day services continues to be an uphill struggle. Adult day centers remain a relatively well-kept secret, and their existence and their value need to be publicized more broadly. Another barrier to expansion is a lack of financing. Services usually follow dollars, and third-party reimbursement for services has been limited to date. There is some hope on the horizon, however. Private long-term care insurance that covers adult day services has seen rapid growth in recent years. Some states are expanding Medicaid coverage and other state funding for adult day services, but this financial expansion is so far modest.

Many government policy-makers worry about the so-called "woodworking effect"—an increase in the use of services due only to the availability of funds—and thus they are reluctant to expand coverage. But some believe that adult day services can be a substitute for more costly in-home or nursing home care, can replace some subacute care such as rehabilitative and mental health services, and can serve people with high-care needs such as those with AIDS. Still others believe that by using the services of an adult day center, caregiver stress can be reduced. These beliefs need to be tested. The field is now ripe for research on outcomes and for studies of cost effectiveness. Such studies are needed if community-based services are to flourish and adult day centers are to remain a practical and appealing part of the solution to long-term care needs.

## Notes

<sup>1</sup> Alzheimer's Association. Sept. 28, 1998. Online: [http://www.alz.org/alzheimers\\_disease\\_facts\\_figures.asp](http://www.alz.org/alzheimers_disease_facts_figures.asp)

<sup>2</sup> N. L. Mace and P. V. Rabins. *A Survey of Day Care for the Demented Adult*. Washington, D.C.: National Council on the Aging, Inc., 1984.

<sup>3</sup> R. Von Behren. *Adult Day Care in America: Summary of a National Survey*. Washington, D.C.: National Council on the Aging, Inc., 1986.

<sup>4</sup> C. H. Asbury and R. S. Henry. "Day Programs for Dementia: Responding to the Market." *Perspectives on Aging* (National Council on the Aging, Inc.), July–Aug. and Sept. –Oct. 1991, 25–28.

<sup>5</sup> M. E. Henry and J. Capitman. "Finding Satisfaction in Adult Day Care: Analysis of a National Demonstration of Dementia Care and Respite Services." *Journal of Applied Gerontology*, Sept. 1995, 14(3), 302–320.

<sup>6</sup> B. V. Reifler, N. J. Cox, B. N. Jones, J. Rushing and K. Yates. "Service Use and Financial Performance in a Replication Program on Adult Day Centers." *American Journal of Geriatric Psychiatry*, 1999, 7(2), 98–107.

<sup>7</sup> B. V. Reifler, R. S. Henry, J. Rushing, K. Yates, N. J. Cox, D. D. Bradham and M. McFarlane. "Financial Performance Among Adult Day Centers: Results of a National Demonstration Program." *Journal of the American Geriatrics Society*, 1997, 45, 146–153.

<sup>8</sup> Ibid.

<sup>9</sup> V. Bell and D. Troxel. *The Best Friends Approach to Alzheimer's Care*. Baltimore: Health Professions Press, 1997.

<sup>10</sup> K. A. Sherrill, B. V. Reifler and R. S. Henry. "Respite Care for Dementia Caregivers: Findings from the Robert Wood Johnson Foundation Projects." In E. Light, G. Niederehe and B. C. Lebowitz (eds.), *Stress Effects on Family Caregivers of Alzheimer's Patients*. New York: Springer, 1994.

<sup>11</sup> G. Newton and R. S. Henry. *Marketing Adult Day Programs: Targeting Caregivers to Reach Participants*. Winston-Salem, N.C.: Bowman Gray School of Medicine of Wake Forest University, 1992.

<sup>12</sup> Alzheimer's Association. Sept. 28, 1998. Online: [http://www.alz.org/alzheimers\\_disease\\_facts\\_figures.asp](http://www.alz.org/alzheimers_disease_facts_figures.asp)

<sup>13</sup> C. Hoffman and D. Rice. *Chronic Care in America: A 21<sup>st</sup> Century Challenge*. Princeton, N.J.: The Robert Wood Johnson Foundation, 1996.

<sup>14</sup> A. M. Reaves (ed.). "Number of Adult Day Centers in U.S. Rapidly Increasing." *Respite Report*, Winter 1993, 5(1), 12.

## EXHIBITS

5.1 Dementia Care and Respite Services: Program Locations

5.2 Dementia Care and Respite Services: Characteristics of 17 Sites at Program End, 1992

5.3 Partners in Caregiving: Program Locations

5.4 Partners in Caregiving: Characteristics of 49 Sites at Program End, 1996