

Brookdale Respite Reporter

Spring 2003

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Implementing the National Family Caregiver Support Program

A significant national change occurred in federal policy in 2000, with the first ever direct funding of services for family caregivers through the Administration on Aging (AoA). Passage of the National Family Caregiver Support Program (NFCSP/Title 3E) as part of the Older Americans Act of 2000 is official recognition of the tremendous service provided by family and informal caregivers in the U.S. The Act initially provided \$125 million allocated to states through a congressionally mandated formula based on each state's proportion of the age 70+ population. Under the direction of AoA, the NFCSP calls for states, working in partnership with Area Agencies on Aging (AAAs) and local community-based agencies, to provide services in five categories:

1. Information to caregivers about available services;
2. Assistance to caregivers in gaining access to supportive services;
3. Individual counseling, support groups, and training for caregivers to assist them in making decisions and solving problems related to their caregiving role;
4. Respite care to provide temporary relief to caregivers from their caregiving responsibilities; and
5. Supplemental services, on a limited basis, to complement care provided by caregivers.

Populations eligible to receive services under the Act include family caregivers of older adults and grandparents and relative caregivers of children ages 18 and younger. The NFCSP requires that priority consideration be given to persons in the greatest social and economic need and to older individuals providing care and support to persons with mental retardation and related developmental disabilities. Locally these funds, ranging from tens of thousands to hundreds of thousands of dollars based on each state's local allocation formula, have served to expand caregiver services in new and creative ways.

With their focus on caregiver services, many local Brookdale National Group Respite Programs have been well positioned to benefit from these new funding streams, as described below. In Virginia for example, Mountain Empire Older Citizens (MEOC), a rural AAA covering three counties, has received \$67,000 per year to develop new services. Selected by the National Council on the Aging as one of five national model caregiver programs, the agency has expanded its capacity, and now includes:

- Eight social model community group respite programs and one medical model adult day care ;
- Expanded in-home respite;
- Availability of respite during support groups;



Recent Developments

In addition to increased support for family caregivers, a new approach to respite is being shaped by organizations around the country to meet the needs of elders in the early stage of dementia. Kristin Einberger, of Garden Haven Adult Day Services in Napa, CA speaks of her vision for the new early stage Mind Boosters Club, "I want the broader community to see that elders with dementia are still vital members of the community." Read more about early stage dementia, caregiver support and group respite programs inside.

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Participants, staff and volunteers enjoy a group activity at Daybreak Respite and Caregiver Support Services, a program of Catholic Charities of San Jose in CA

National Family Caregiver Support Program

- An Alzheimer's/Caregiver's library, including computer/internet access;
- Educational programming, including an annual Alzheimer's seminar and a physician education program called Making the Link ;
- Five caregiver support groups, including two that are dementia-specific;
- Additional supportive services, including transportation, medical supplies, and home-delivered meals; and
- Expanded kincare services for grandparents and other relatives caring for children, including hiring of a full-time coordinator.

Julia Trivett-Dillon, MEOC's Director of Family Support Services, notes that her agency was in an ideal position when the NFCSP/Title 3E funds became available. Having begun developing caregiver-focused services 20 years ago, MEOC decided to use these new funds to expand its breadth and depth of caregiver programming.

In other rural counties, AAAs are also providing direct services, due mostly to a lack of contractors and infrastructure outside of the AAA.

Chenango County, NY is spending its \$25,000 allocation on its two AAA-sponsored adult day programs and outreach for those programs.

In less rural counties, services are typically being contracted through local community-based agencies. In Huron, Sanilac, and Tuscola counties in Michigan, qualifying caregivers are provided with vouchers of \$1,000 per year to purchase respite services (in-home, day services, and overnight) from local providers, including the Human Development Commission (HDC), an agency with three group respite sites. HDC bills the AAA each month for eligible clients, and currently provides vouchered respite services to 18 families. In HDC's fourth county, Lapeer, the agency is funded through an AAA contract to provide caregiver training, counseling, and support services.

While group respite/day services are frequently being funded through NFCSP/Title 3E funds, other supportive services are also being provided by Brookdale sites. In Clackamas County, OR, the Canby Adult Center has contracted to provide caregiver assistance, information & referral, and case monitoring along with its group respite services. In Gila County, AZ, case management is the local emphasis, and Catholic Community Services of Southern Arizona has a contract to provide that service for

caregivers of older relatives as well as for grandparents and other relative caregivers of children. Senior Services for South Sound in Olympia, WA has contracted with the local AAA to provide caregiver retreats and a peer-mentoring program. The agency hosted two retreats in 2002 for 22 caregivers and has a cadre of 15 trained peer mentors working with and supporting local caregivers.

Because the federal government provided flexible guidelines and local AAAs are the conduits for funds to communities, there is a great deal of variation in service patterns across the country. Agencies noted that local decisions about funding priorities were determined through community processes including forums, focus groups, surveys, and other methods to get input from caregivers and service providers about local service needs.

The greatest challenge to local communities is holding on to new and expanded services in a time when many local and state governments are looking to cuts in order to balance underfunded budgets. In its 2003 budget, for example, Chenango County, NY will no longer fund the overnight and in-home respite it provided in 2002. Gila County, AZ is no longer able to fund its "Mini Programs" grants initiative, which was providing overnight respite, medical/personal care products, nutrition counseling, and adaptive devices. Staff at Senior Services for South Sound describes its ability to continue its caregiver retreats and peer mentoring program in 2003 as "iffy."

Despite these hopefully short-lived challenges, it is clear that the NFCSP is providing significant recognition to and funding for a long overlooked segment of the older adult population: *family caregivers*. For any agency seeking to develop services through NFCSP/Title 3E, the local AAA is the place to begin. For more information visit the AoA website at www.aoa.gov.



The Brookdale Network's National Impact

The Brookdale National Group Respite Program (BNGRP) is a network of social-model day service programs which provides opportunities for people with dementia to meet in groups outside of their homes. It stresses socialization, recreation, and maintenance of participant functioning. The program began as a pilot program in 1985 as the Brookdale Community Respite and Group Services Program through the Brookdale Center on Aging of Hunter College, to serve individuals with Alzheimer's and their caregivers in and around New York City. In 2003, BNGRP consists of 168 agencies operating 210 sites in 36 states.



Staff, Deena Gibson and Kelly Trudell celebrate Mardi Gras with participants of the Greater Michigan Alzheimer's Association's Helping Hands Group Respite Program in Detroit, MI

In the mid-1980s, there were few respite options available for families caring for loved ones with dementia. Repeated studies showed that respite was the most requested service option by caregivers. Caregivers were forced to rely upon family members, friends, and neighbors to provide temporary care, or pay a high hourly rate out-of-pocket for a home care aide. Day service programming was in its infancy.

Program History

The Program was designed to provide a low cost, high quality and cost effective respite option for caregivers of dementia patients. To meet these criteria, the group setting was chosen. While it could be high quality, one-on-one home care was neither low cost nor cost effective. Group settings, with their "economies of scale," could meet the low-cost and cost-effective criteria, and, with training and technical assistance,

could be of high quality. The group setting offers the added advantage of providing social outlets for individuals, both participants with mild to moderate dementia and their caregivers, who are at high risk for isolation.

Initially, the program was envisioned purely as a respite program; that is, one which existed for the purpose of providing temporary relief to caregivers from their caregiving role. It quickly became apparent, particularly to local site directors conducting outreach, that such a program which provided a break from the duties of caring for a loved one, was difficult for caregivers to accept. The guilt of receiving respite in and of itself was overwhelming. Caregivers needed to see the benefits of the program for the participants and needed to be sold on the program with that in mind.

The Brookdale Model Today

Currently, BNGRP has two distinct yet interwoven goals: To offer opportunities for people with Alzheimer's disease or a related dementia to engage in a program of social and recreational activities in a secure and supportive environment; and to provide respite to family and other primary caregivers. In order to meet these goals, the program established a set of basic principles and guidelines in delivering a package of core services. These include:

- A program that is dementia-specific, serving two populations—dementia clients and their family caregivers;
- Structured group activities designed to provide socialization and cognitive stimulation, maximizing remaining functional and cognitive skills according to the needs of individual participants;
- Services provided in groups that range in size from four to 15 or more;
- Professional staff leadership supported by trained aides and volunteers;
- Regular hours of operation—at least one day per week, four hours per session;
- Comprehensive assessments, care planning, and clearly defined intake and discharge criteria;
- Appropriate program space including secure, comfortable, home-like environments and facilities;

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The Brookdale Network – *Continued from page 3*

- Access to supportive services for family caregivers including individual and group counseling, information and referral services, and support groups; and
- Education and training programs for family caregivers and community members.

As a result of this intervention, expected outcomes include: A decrease in caregiver burden including better health and lower levels of depression; delays in institutional placement of Alzheimer's patients; and maintenance of participants' functional and social skills.



A participant from My Friends Place, a program of the United Methodist Church in Bangor, ME

Program Accomplishments

Quality Programming for Participants and Respite for Caregivers

Brookdale-funded programs have provided more than 13,500 people with adult day programming and over 5 million hours of respite for their caregivers. Social-model adult day services can meet the needs of dementia families appropriately and effectively without the extra cost burden of unnecessary health care. This model is designed for elders in the mild to moderate stages of Alzheimer's who, generally do not require the more intensive, ongoing medical monitoring that a adult day health program provides. Because this model is so cost-efficient, high quality services for Alzheimer's families have been successfully developed in communities where few services previously existed.

A Flexible Adult Day Service Model to Meet Diverse Needs

This form of day service continues to be implemented successfully by a wide range of sponsors and communities. The model stimulates coalition building within communities to meet the needs of local Alzheimer's families, and fosters larger collaborations to develop high quality care for persons with dementia. Program flexibility and responsiveness to local needs have led to positive long-term outcomes.

Long-Term Viability and Continuity

Of the BNGRP programs funded nationally since 1989, more than 85% are still in operation. The seed grant approach encourages programs to plan for fundraising activities from the start, and obtain significant in-kind and financial resources to maintain and expand services. Group respite programs in BNGRP's growing national network have sustained services beyond the \$10,500 two-year seed grant and remain viable community-based services. On-going technical assistance and training are instrumental in fostering the development, expansion and continuity of programs.

2002 National Program Statistics

Units of Service

811, 710	Hours of Group Respite Provided
4493	Program Participants* Served
4143	Family Caregivers Served
1515	Caregiver Support Groups Provided
1162	Caregiver Education Sessions Conducted

** Elders with Alzheimer's or Related Dementia*

Summary

Day services generally, and the Brookdale National Group Respite Program, are options for families facing Alzheimer's disease. These programs have become central components of the health and long-term care continuum. A variety of programs has evolved to meet an array of needs among participants with mild to moderate dementia and their family caregivers. These programs exemplify the resourcefulness of services providers in addressing the differences in participants' needs, based on the nature and severity of a participant's impairment, a

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Trends in Early Stage Care and Programming

A person with early stage Alzheimer's, according to the Alzheimer's Association, will often sense changes in his or her ability to recall events; manage household tasks; make decisions; express ideas, thoughts, and feelings; understand other people when they are talking; or handle complex work such as balancing a checkbook. A common reaction on the part of both those suffering from memory loss and those who love them is to try to hide these changes due to fear and the stigma associated with the disease. This denial, albeit a natural reaction, can work against the best interests of all involved because it may delay or prevent prompt medical care and appropriate social support. In this article, some interesting developments and trends in the care of elders with early stage Alzheimer's will be explored.

Alzheimer's Disease (AD) is a progressive illness, that for descriptive purposes, is divided into three stages: early, middle and late. Elders with Alzheimer's live many years with the disease, with the majority of the years spent in the early, high-functioning stage of the disease. According to the second edition of the book, *Alzheimer's Early Stages: First Steps for Family, Friends and Caregivers*, by Daniel Kuhn, M.S.W., there are currently an estimated 5 million Americans with AD, but that number is expected to rise along with the growing aging population.

A diagnosis of AD is often met by families and those diagnosed with some combination of fear, sorrow, anger and confusion. Persons with Alzheimer's and their families may fear an unknown future of what AD will look like. They may experience grief when they consider the many losses Alzheimer's brings with it, especially the loss of identity. Finally, a diagnosis such as Alzheimer's can be overwhelming and confusing; most people don't know much about the disease, how it progresses and what they should do about it.

On the other hand, some families are relieved to finally learn a medical cause for the worrisome changes in memory and behavior. For professionals and families alike, there are now many tools and much more information available to help people with AD. If diagnosed early, these tools, as well as research that provides constantly updated information, can make a significant impact in the lives and well-being of people with Alzheimer's. The importance of early diagnosis cannot be overemphasized. The following list outlines some key reasons for seeking an accurate diagnosis, according to Daniel Kuhn. Reasons for obtaining a diagnosis are to:

- Rule out reversible forms of dementia
- Begin AD drug treatment
- Provide a context and explanation for symptoms
- Obtain appropriate medical equipment
- Let you decide whether or not to enroll in research studies
- Help you understand your changing roles and responsibilities
- Ease communication among all concerned
- Plan for the future

One reason why information about early stage AD is expanding so rapidly is that the bulk of research dollars are being applied to that very topic. This

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Specialized Early Stage Respite Programs

Earlier intervention has long been the goal of professionals who work with Alzheimer's families. Respite programs are one of the supportive services available that offer benefits to both family members and elders with AD.

Over the last several years, we have seen the emergence of early stage respite programs that follow the fundamental principles of the Brookdale model, but are tailored to the particular needs and desires of adults living with early stage AD. At this stage of dementia, a person is very aware of the cognitive changes that he or she is experiencing. In the respite programs that have been developed recently, program participants played a significant role in the design and format of the program.

This participant-directed approach has been very successful for the Silver Club CoffeeHouse at the University of Michigan's Turner Geriatric Center, in Ann Arbor, MI. The Silver Club CoffeeHouse was launched as a one-day per week respite program in 2001, as a natural progression of an early stage support group that was offered as a ten week education and support session.

In this support group, participants diagnosed with dementia expressed the desire for a place to meet on an ongoing basis that focused on togetherness, exercise, outings, educational opportunities, enriching activities and regular mutual support. Today, the CoffeeHouse, as the program participants named their program, is a direct reflection of the vision and design of support group members. Amy Kruger, Program Coordinator who co-facilitates the weekly program, explained that although spouses and families benefit from respite away from the duties of assisting their loved ones, elders at this stage do not wish to attend adult day care or respite programs per se, thus the more appropriate reference to the "club."

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Specialized Respite

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Other organizations also report that elders with newly diagnosed AD will often reject a program that is geared to elders in the middle to later stages of AD. At this stage, visiting such programs can be upsetting, and trigger fear as Arlene Kershaw of Easter Seals in Manchester, NH explained. After observing this reaction a number of times, it became clear that adults with early stage Alzheimer's would be best served in a special manner. Easter Seals now offers the Brookdale Club, a three-day per week program that highlights regular outings. An emphasis on outings seems to be a common theme among early stage respite providers. In fact, Seniors' Resource Center in Denver, CO aptly named its new early stage program, Out N' About at Day Break.

In April, Garden Haven Adult Day Services of Napa, CA opened the doors of its newest component in a continuum of care for Alzheimer's families—The Mind Boosters Club, a specialized program that features proactive, memory enhancing activities. As the program gets underway, participants will plan and develop the program further by choosing a permanent name, establishing a program agenda and selecting community involvement projects in which to be engaged.

Kristin Einberger, Program Manager, along with other staff, carefully planned the Mind Boosters Club over the course of almost two years, with substantive input from the Napa Valley Alzheimer's Coalition. The catalyst for the development of this community-based program in Napa was the increased frequency of requests for services from families with a recent diagnosis of AD. The goals for participants of this program are to foster friendships, prevent isolation, maintain dignity and self-worth and learn useful techniques to cope with memory loss.

These programs, which provide an atmosphere of total acceptance and ample opportunities to succeed, are stellar examples of the positive impact that can be achieved with early diagnosis and sensitive intervention.

Early Stage Trends *Continued from page 5*

year, for example, the National Institutes of Health (NIH) and the National Institute on Aging (NIA) are spending upwards of \$600 million on Alzheimer's research, with studies that include early stage drug trials and alternative supplements such as ginkgo biloba, and brain imaging studies that will help improve the accuracy of early diagnosis.

An exciting area of research is memory training. In one study published in the October, 2002 edition of *Neuropsychology*, memory training such as mnemonics, which uses meaningful word associations to help trigger memory, was shown to be effective for some people. As a whole, the group of 12 participants with AD, an admittedly small sample size, enjoyed significantly improved memories, which they sustained after six months even without practice.

Given the current knowledge base and research results available today, what can individuals with early stage AD do to maximize their health, maintain their cognitive functioning and organize their lives? Many people are learning about the number of drugs on the market that can prove beneficial. According to the Family Caregiver Alliance, as of 2002, four drugs had been approved by the FDA, namely Donepezil (Aricept), Rivastigmine (Exelon), Galantamine (Reminyl) and Tacrine (Cognex) (although this drug is no longer actively marketed). These drugs work more effectively during the early stages of the disease and, as with most medications, may have unwanted side effects. It is also possible to be part of clinical trials testing new drugs.

People with memory loss are able to lead active lives with appropriate support and lifestyle enhancements. Close association with a memory center that has a multidisciplinary team and experience with AD can put people in touch with the resources available to them personally and in their larger communities. Mood managing medications, diet, exercise, and other self care measures are important for people with early stage Alzheimer's. There are also support, social and creative arts programs available for people in the early stages of AD.

An exciting development is that elders with early stage dementia are writing books, being featured as public speakers and becoming involved in shaping programs. In fact, the Ypsilanti Area African American Alzheimer's Council in Michigan featured a panel of three participants of a local early stage respite program for its June, 2002 *It's a Family Affair Conference*. In the closing session of the conference, participants from The Silver Club CoffeeHouse, in Ann Arbor, MI, spoke first-hand of their experiences living with memory loss. At the National Alzheimer's Disease Education Conference, to be hosted by the Alzheimer's Association, in Chicago, IL, in



A CoffeeHouse participant (left) as a panelist at the It's a Family Affair Conference in Ypsilanti, MI. Amy Kruger is on the right.

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The Priceless Contribution of Volunteers

In February, 2003, *The Philanthropy News Digest* announced that the Independent Sector, "a coalition of philanthropic organizations dedicated to strengthening the nonprofit sector," has increased the value of volunteer time by almost 50 cents to \$16.54 an hour. Although it is difficult to place a dollar amount on the value of volunteers in a service organization, this announcement clearly illustrates how much the nonprofit sector relies on the power of volunteerism.

In the United States, 59 million individuals reported volunteering in the Current Population Survey conducted in September, 2002 by The Bureau of Labor Statistics, according to the *Chronicle of Philanthropy*. The survey, which polled 60,000 U.S. households, provided the data to conclude that one in four Americans regularly give their time to one or more organizations.

This level of generosity and commitment is also seen in Brookdale programs across the country. For instance, in the year 2002, volunteers provided 184,532 hours of service for the benefit of elders with dementia

and their family caregivers. The range of services volunteers perform in respite programs includes program planning as advisory committee members, clerical duties, fundraising, preparing meals, providing transportation, assisting with group activities and working one on one with program participants.

Volunteers who work directly with respite program participants respond to participants' needs and assist with functions such as feeding, walking and toileting, or program activities including games, creative projects, exercise and outings.

Respite program volunteers receive training in dementia care and ongoing supervision by the professional staff, in order to develop the skills and

knowledge that are necessary to compassionately and patiently respond to elders with dementia.

Volunteers contribute to the success of respite programs in myriad ways, but most importantly, it is the warm, safe, caring environment that a corps of committed volunteers creates



A participant and program volunteer take a stroll together at a respite program initiated by the Brookdale Center on Aging at Hunter College

Early Stage Trends and Care

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July, 2003, the opening plenary session will feature a dialogue with three individuals diagnosed with AD and members of their respective families.

For the first time, individuals with early stage Alzheimer's will co-present a web-based seminar series along with professionals. The on-line series, sponsored by the American Society on Aging, entitled *Early Stage Alzheimer's: Understanding the Experience, Meeting the Needs*, will be presented in four 90 minute sessions from May 12 - June 9, 2003. For more information, visit www.asaging.org/webseminars.

The sooner the disease is diagnosed and its implications understood, the better-equipped individuals are to contribute to planning the course of their own lives from both legal and financial perspectives. At this point, individuals can make decisions about living arrangements and other care options. They can learn all there is to know about the disease, get involved with the Alzheimer's community, and perhaps most importantly, spend quality time with family and friends or doing things for themselves that they may have put off. With what is known today, families can benefit from the best care available and take advantage of on-going advances in medical and social sciences.

Brookdale National Group Respite Programs

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caregiver's ability to cope and the availability of local resources. Social-model day services allow communities to respond to the needs of Alzheimer's families with quality care in a cost-effective and appropriate manner. As we strive to meet the challenges of the expanding population of Alzheimer's patients, the social-model group respite program serves as an important link in the continuum of community-based dementia services.





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Participants at My Friends Place, a program of the United Methodist Church in Bangor, ME

2003 Group Respite Grants Available

We are pleased to announce the BNGRP Request for Proposals (RFP) to develop new social model, dementia-specific group respite programs for Alzheimer's families. Grant applications are due on July 10, 2003. Non-profit organizations and public agencies are eligible to apply. Grantees will be funded for up to two years (\$7,500 in the first year, renewable at \$3,000 in the second). Agencies must develop an adult day program that includes:

- Dementia-specific services serving two populations – the dementia participants and their family caregivers;
- Structured activities designed to provide socialization and cognitive stimulation, maximizing remaining functional and cognitive skills according to the needs of individual participants;
- Services provided in small groups (five to 15) outside of the home;
- Professional staff leadership supported by trained volunteers;
- Regular hours of operation, with availability of at least one day per week, four hours per session;
- Individual assessments, care plans, and defined admission and discharge criteria; and
- Access to supportive services for caregivers such as support groups, information and referral services, and education forums.

This service must be a new initiative; expansion of existing dementia programs or the extension of days or hours is excluded. In addition to direct financial support, grantees receive an orientation and training, scheduled for November, 2003 in Secaucus, NJ, and ongoing technical assistance.

Grant applications are due on **Thursday, July 10, 2003**. To receive RFP guidelines and a grant application, or to request a free copy of the publication *How to Start and Manage a Group Activities and Respite Program for People with Alzheimer's Disease and Their Families*, please contact Evelyn Yuen, TA Resources Manager, Phone: (510) 540-6734, Fax: (510) 540-6771 or e-mail: bngrp@best.com. For more information, please visit our website at www.brookdalefoundation.org.

The Brookdale
National Group Respite Program

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*Photo on the Cover: Participant and
volunteer Santa from Cass County Council
on Aging, CoA Adult Day Services in
Cassopolis, MI.*