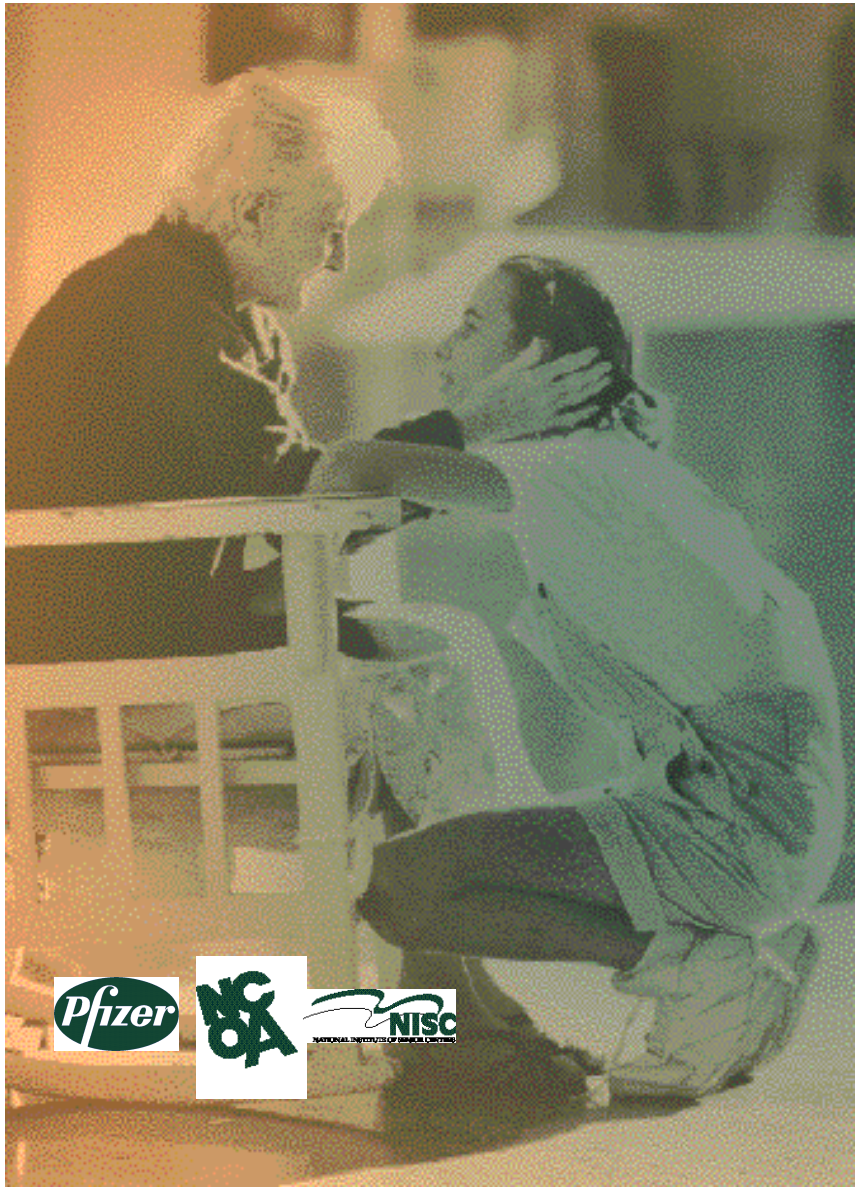




A photograph of a woman in a light blue hospital gown sitting on the edge of a hospital bed, holding the hand of an elderly woman with white hair who is lying in the bed. The scene is dimly lit, with a warm, orange glow. The text "TOGETHER WE CARE: HELPING CAREGIVERS FIND SUPPORT" is overlaid on the left side of the image.

**TOGETHER
WE CARE:**
**HELPING CAREGIVERS
FIND SUPPORT**



TOGETHER
WE CARE:
HELPING CAREGIVERS
FIND SUPPORT



Pfizer Inc
235 East 42nd Street
New York, NY 10017



The National Council on the Aging
409 Third Street, SW
Washington DC 20024



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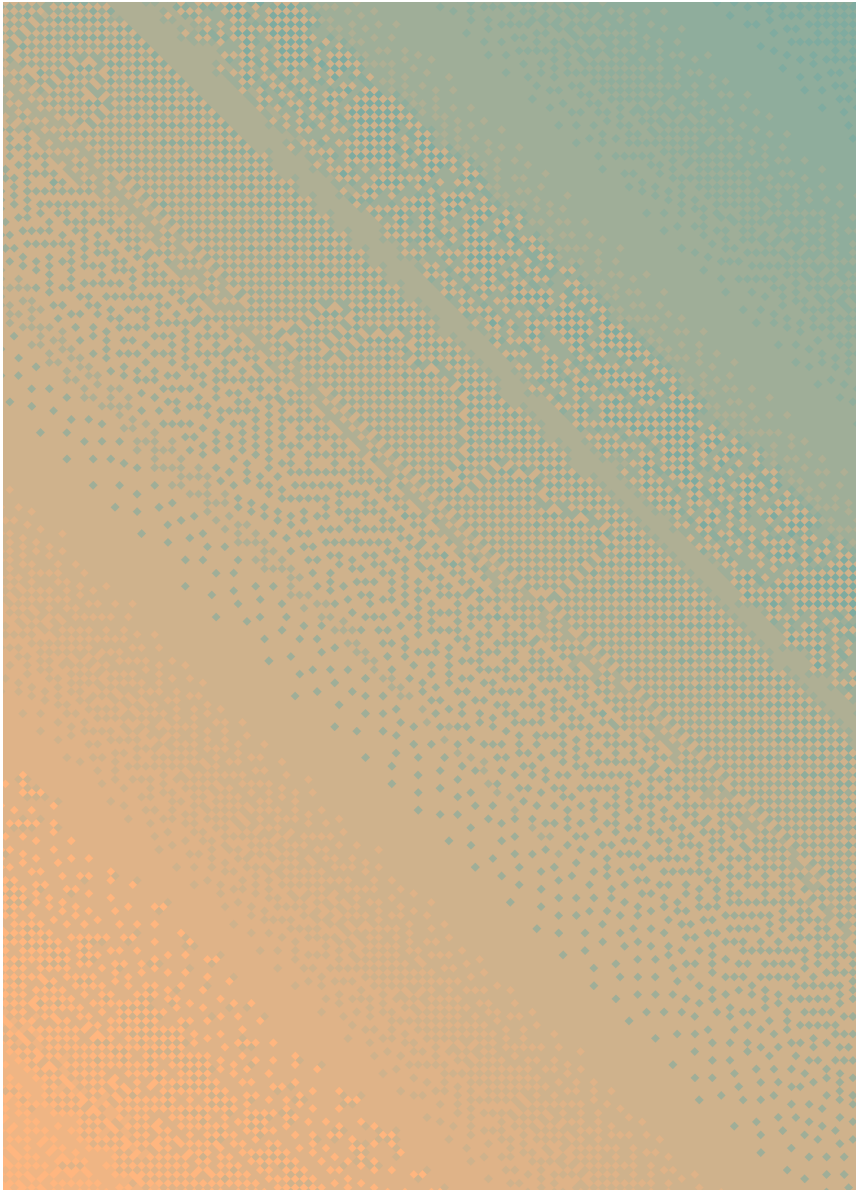
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Who We Are

NCOA is the nation's first association of organizations and professionals dedicated to promoting the dignity, self-determination, well being, and contributions of older persons.

We began in 1950 with a new concept of older people as "the aging," not the "aged," and we embraced the challenge of creating a nation where many more people, especially disadvantaged, frail, and minority elders, would live much longer and better lives.

NCOA's members include senior centers, area agencies on aging, adult day services, faith congregations, senior housing, health centers, employment services, and consumer organizations. Many leaders from academia, business, and labor also join NCOA to support our mission and work.

What We Do

We help community organizations to enhance the lives of older adults. We turn creative ideas into programs and services that help older people in hundreds of communities. We are a national voice and powerful advocate for public policies, societal attitudes, and business practices that promote vital aging.

Over the past half century, NCOA has shaped many innovative aging programs such as Meals-on-Wheels, Foster Grandparents and Family Friends. NCOA is a center of leadership, innovation, and nationwide expertise with a diverse national membership of more than 7,500 organizations and individuals.

CURRENT PROGRAMS AT NCOA INCLUDE:

- ▶ National standards and accreditation programs for adult day services and senior centers;
- ▶ The Consumer Information Network, a partnership of NCOA members and other community-based organizations established to distribute information and educational programs to older consumers and their families;
- ▶ Older worker training and job placement to assist 10,000 low-income participants annually and provide technical assistance to employers and training specialists;

▶ Advocacy programs that support legislation to strengthen protections for older people in such areas as healthcare, home- and community-based services, economic security, housing, and employment;

▶ Family Friends, an intergenerational volunteer program that matches mature men and women with children and families at risk.

Visit the National Council on Aging at www.ncoa.org.

The National Council on the Aging
409 Third Street, SW
Washington DC 20024
202-479-1200



Pfizer Inc is a research-based, global pharmaceutical company. The company discovers and develops innovative, value-added products that improve the quality of life of people around the world and helps them enjoy longer, healthier, and more productive lives. Pfizer has three business segments: healthcare, animal health and consumer healthcare. Its products are available in more than 150 countries.

Innovation and community focus are two of Pfizer's core values. As a reflection of these values, Pfizer's Medical & Academic Partnerships group (MAP) is pleased to maintain a commitment to the health and care of our aging population. This commitment is expressed through a range of initiatives designed to support innovative research and the development of model leadership efforts in the field.

Specific programs include:

- ▶ Pfizer/American Geriatrics Society Foundation for Health in Aging Junior Faculty Scholars Program for Research on Health Outcomes in Geriatrics 2002
- ▶ American Federation for Aging Research (AFAR)/Pfizer Research Grants in Aging
- ▶ Pfizer/American Society on Aging (ASA) Managed Care and Aging Awards Recognizing Innovation and Quality

Pfizer is proud to partner with NCOA in bringing knowledge to professional care providers as they counsel family caregivers. This program is MAP's most recent initiative to provide model projects to community based care giver providers as they strengthen and support the invaluable contribution made by family caregivers.

Visit Medical and Academic Partnerships at www.physicianscientist.com

Pfizer Inc
235 East 42nd Street
New York, NY 10017



INTRODUCTION

TOGETHER WE CARE: HELPING CAREGIVERS FIND SUPPORT

Physicians and other health professionals often find that their strongest allies in helping patients deal with chronic, debilitating illness are the families of patients. According to the Bureau of the Census, from 1995 to 2010, the oldest old cohort (aged 85 and older) is expected to increase more than four times as rapidly than the population aged 65 to 84. The National Long Term Care Survey (1994) estimates there are more than seven million persons serving as informal caregivers and the likelihood of families serving as informal caregivers increases tremendously in the next decade. This booklet aims to help professionals direct caregivers to useful sources of information, as well as stimulate additional programming to help the work of caregivers.

Without help, caregivers will potentially weaken and need help themselves -- stress and worries of many kinds, as well as difficult duties, take their toll. A Family Caregiver Alliance survey found that 76 percent of family caregivers need respite of one kind or another. For example, respite for some people may be a few hours off for recreation or to simply tend to household chores they might otherwise neglect. For others, respite may be regular attendance at support group meetings. For still others, it may be an in-home service that eases the daily workload. For many, respite may be a combination of these and other services.

But respite and supportive services do not come easily. They require organized response and recognition of certain guiding principles and this booklet reports on five exemplary programs. In each program, private citizens or public agencies have recognized that communities cannot ignore the unprecedented and growing demands on family caregivers.

Innovatively and persistently, the programs on the following pages are assisting in ways to help caregivers. In a major metropolis, in a bedroom community near a capital city, in a sprawling three-county corner of Appalachia, in a scenic Montana valley, and in the largest city in Alaska, practitioners and volunteers have worked together to make respite service programs successful.

Although varied, the programs follow similar principles: respect for the people they help, teamwork, and a determination to supplement, rather than duplicate, existing services. These pioneers must often comply with traditional attitudes even as they attempt to alter them.

A recurring theme in most of the interviews conducted for the data in this booklet, for example, was the reluctance of many caregivers to seek help, even when on the verge of physical exhaustion. The most common reason given -- the caregivers (and sometimes, the care recipients) felt they were somehow failing to cope with a basic family responsibility if they acknowledged a need for support.

Caregiver respite and service providers must often find tactful ways to convince caregivers they can work even more effectively when they accept help. While in some areas, long waiting lists testify to caregiver willingness to embrace assistance.

The authors hope this booklet will provide useful information to professional care providers attempting to counsel family caregivers on sources of support and respite. It may also give aging specialists models they may wish to replicate or adapt to their own organizations. In addition, the booklet is intended to help the general public realize that practical help can be made available when communities respond positively.

Two appendices give additional information on sources of support for caregivers and The National Family Caregiver Support Program.

HOW THE PROGRAMS WERE IDENTIFIED

NCOA recently completed a landmark national survey of 628 reputable, high quality and/or innovative community-based programs in the areas of social support, caregiving, chronic disease self management/health promotion and physical activity. Representatives from three national organizations* identified leaders in the field of aging to nominate programs to this study. The study was supported by The Robert Wood Johnson Foundation.

Analysis of the results provided a comprehensive look at many important program areas including specific services, clients, funding, partnering, strategies to strengthen quality, as well as barriers to promoting program expansion. With the assistance of a panel of caregiving experts, components of exemplary programs in caregiving were identified and applied to the database. From a wide field of worthy programs, 10 outstanding programs were subsequently selected for in-depth telephone interviews using a protocol developed with the help of our expert panel. Five of those programs are included in this publication.

*The National Council on the Aging and its National Institute of Senior Centers, the National Association of Area Agencies on Aging, and the National Association of State Units on Aging.

BOZEMAN SENIOR CENTER ADULT DAY SERVICES

BOZEMAN, MONTANA

An adult day service center within the Bozeman Senior Center draws upon the strengths of both centers to develop the caregivers support program.

SPONSORING ORGANIZATION

Incorporated in 1969 as a nonprofit organization, the Bozeman Senior Center established the day service in 1997 in recognition of intensifying demand on family caregivers. Caregivers should have respite "to do what they like to do and have to do." The facility housing both centers is described as "newly remodeled, beautiful and the first of its kind in Montana."

Inclusion of the day center within a senior center gives the program important links to other services, including meal programs. Service extends beyond the city (population, 30,000) to a rural, scenic area of south central Montana. Membership is open to anyone over age 50 and current enrollment is more than 1,700. The adult day service center gives continuity to senior center participants who have become frail over time by creating an opportunity to continue participating in an activity they highly value -- going to the center. Just as important, the Center can become a place of activity and respite for the caregiver. Illnesses with which caregivers cope include Alzheimer's disease, depression, stroke, Parkinson's disease, and diabetes.

ASSISTANCE PROVIDED

Services provided by this adult day service center include meals and other nutritional support, case management (made possible by a Medicaid waiver), socialization, exercises, games, other activities, a free medical equipment loan program, and transportation to medical appointments.

This adult day service center can serve up to 12 persons per day on weekdays, and is closed on weekends. Center vehicles may travel 30 to 40 miles one-way outside of Bozeman city limits to pick up clients; severe winter weather may cause temporary cancellation.

Family caregivers find support through annual training and frequent information updates, some through radio talk shows that help them remain up to date on ways to deal with illnesses or disabilities. Depending on the nature of the family member's illness, respite may be for provided for several hours on one day or may

extend for the better part of a week. Weekly visits to the senior center by occupational or speech therapists, even a podiatrist, eliminate the need for caregivers to take family members on separate visits to such specialists. Staff may refer caregivers to support groups and maintain telephone contact with long-distance caregivers.

Caregivers range in age from 32 to 83, and 60 percent are employed full-time; most are adult children. In addition to the transportation provided by the Center, various collaborative efforts are arranged to transport the care recipients.

QUALITY OF SERVICE

"We are committed to individual growth and maximizing one's abilities in a respectful, dignified, and compassionate atmosphere. We strive to provide resources and education for caregivers and the community as an integral part of the long-term care continuum in the Gallatin Valley."— Bozeman Adult Day Center brochure.

A guiding question in the program's assessment of services is: how well are we helping the caregiver and the care recipient to live as independently and normally as possible? A "caregiver burdens/demands " assessment, conducted at intake and at intervals, helps determine whether the caretaker's work or worry load is diminishing. This review may give rise to change in resources provided to the caregiving family.

PROGRAM RESOURCES

Staffing: Two full-time, assisted by two part-time workers at intervals.

Volunteers: 15 at the day center and 350 over a year at the senior center.
High school aged to 90+. Volunteer base includes Senior Companions, a national program.

Funding: For eligible participants, a Medicaid waiver makes case management service possible at no cost, and some participants have private health insurance that contribute towards costs. Other sources include a county allotment, United Way, and personal and business donations. All day care clients pay fees determined through a preliminary interview to determine level of payment and scholarships are available for those unable to pay. The Senior Center Foundation accepts gifts of cash, stocks, bonds, and property as tax deductible donations.

In 2001, the caregiver program became self-sufficient. The budget is \$67,700 for 2001, as compared to \$38,500 when the program started 4 years ago.

PARTNERSHIPS

Volunteers and interns provide marketing and additional help. Assistance comes from Rotary and Lions Clubs, Foresters Society, and the Catholic Diocese. Another major source of income is the annual garage sale.

About 20 percent of referrals come from physicians, hospitals, home health care, and others. Most referrals are word of mouth from family's friends or senior center members.

RECOGNITION

"Twenty years of progress, thanks to the city of Bozeman, a very supportive Bozeman community, boards of directors over the years who have looked ahead to meet the current needs of seniors, a very dedicated staff, and senior citizens who enjoy living active, healthy lifestyles. Now we can enjoy being a part of the next 20 years." — Bozeman Senior Center 20th Anniversary Statement, May 21, 1999.

Bozeman Senior Center activities are frequently cited in the city's print media, and staff serve as experts for issues related to aging.

FUTURE GOALS

Extending transportation service by securing funds to purchase a new van.
Providing weekend service and creating reciprocal partnerships with banks.

ADDITIONAL INFORMATION:

CONTACT: Lynell Morrison-Nelson, Program Director, Bozeman Senior Center
807 North Tracy, Bozeman, MT 59715, Phone 406 586-2421, Fax 406 586-7739.

E-mail: bozsctr@mcn.net

CARE LINKS

CLIFTON PARK, NEW YORK

An innovative, multi-purpose senior center relies on community volunteers to provide supportive, non-medical services to seniors and caregivers in need of help in a rapidly growing bedroom community about 20 miles north of Albany, the state capital.

SPONSORING ORGANIZATION

Shenendehowa Senior Citizens Inc. established the Care Links Interfaith Community Caregivers program in 1996 with the help of both a Robert Wood Johnson Foundation and a Charitable Venture Foundation grant. The program's goal, "Linking Those in Need With Those Who Care," helps to keep people living independently in their homes as long as possible without duplicating other, well-established services. Care Links was born out of a growing conviction that seniors and their caregivers in need of respite were sent away from the Senior Center, or remained in the community without the help they needed.

ASSISTANCE PROVIDED

Trained volunteers provide no-cost supportive services to persons 55 and over. Services include: friendly visiting, transportation, respite assistance, shopping and errands, meal preparation, handy helping, telephone reassurance, as well as information and referral.

Caregivers served by the program include spouses, siblings, or adult children, but typically they are women caring for a parent, or a spouse. Volunteers give respite, which is vitally important to caregivers. One caregiver declared, "it gives me a life!" Volunteers help by serving as extra hands for the caregiver. They shop for food, run errands, make phone calls, provide reassurance by telephone when not on a visit, and relieve the caregiver of other routine tasks. If transportation is needed to a doctor's office, volunteers will drive, protected by their own insurance and a liability insurance policy covering the Center. Sometimes just being there to talk or even more importantly, to listen to the caregiver, is an invaluable stress reducing technique.

QUALITY OF SERVICE

"Almost every week someone calls with a need for a program like Care Links. We're so grateful that our dedicated community volunteers and staff can help them." Maia Newman, Executive Director, Shenendehowa Senior Citizens, Inc.

PROGRAM RESOURCES

Staffing: A Program Director (25 hours/week), Office Assistant (20 hours/week), and MSW Student Intern (2 days/week for 9 months/year) are assisted by the Center's Executive Director, Development Director and Financial Records Clerk.

Service provided: 93 volunteers donated 356 hours of time and served 65 care recipients in April 2001.

Funding: Support for the year 2001 is provided by the United Way, the William Gundry Broughton Charitable Private Foundation, Inc., a one-time, mini-grant from the County Office for the Aging, an anticipated legislative grant administered by the State Office for the Aging, and donations (both cash and in-kind) from care recipients, families, congregations, businesses and the community. The budget for 2001 is \$65,991.

FUTURE GOALS

To secure an ongoing funding source and to establish an endowment. Service may be expanded to include community education efforts -- in schools and the business community -- on the rewards and consequences of a rapidly growing older population.

ADDITIONAL INFORMATION

Contact: Maia Newman, Executive Director, Shenendehowa Senior Citizens, Inc.
15 Town Hall Plaza Clifton Park, NY 12065, Phone 518 383-1343,
Fax 518 383-5942.

E-mail: mnewman@nycap.rr.com

DAY BREAK ADULT DAY CENTER

ANCHORAGE, ALASKA

An adult day service program supports caregivers in preventing or delaying institutional care for older persons with Alzheimer's disease or other forms of dementia.

SPONSORING ORGANIZATION

Day Break Adult Day Service Center operates under the aegis of the nonprofit Anchorage Community Mental Services, Inc., more commonly known as Southcentral Counseling Center (SCC). Day Break, which was formed in 1982, is now a component of the broader Senior Services unit at SCC which was established in 1974. Day Break serves approximately 60 individuals and their families each year and has an average daily attendance of 25.

ASSISTANCE PROVIDED

The day service center is open five days a week from 7:30 A.M. until 6 P.M. It includes activities such as: interpersonal group contact, handicrafts, cooking, current events discussion, community outings, physical exercise, gardening and music. Pets are brought to the center on a regular basis to provide healing and therapy. To enhance a sense of belonging, participants are referred to as members, instead of patients or clients. Psychiatric evaluations, ongoing symptom management, individual and family counseling and case management services are available to all Day Break members through the agency's Senior Service programs. Members are more effectively served because staff is familiar with symptoms typically associated with dementia, such as hallucinations, depressions, anxiety, and sleep disorders. A staff geriatric nurse helps families manage members' medications and coordinates care with primary physicians.

Respite hours for family caregivers, most of whom are members' middle-aged offspring and employed, are made possible by the member's time at Day Break. Depending upon the individual family situation, a member may be transported to the center five days a week or for only a few hours on a specific day. Caregivers are encouraged to use their time off not only for essential chores, but also for recreation with friends or other personally satisfying pursuits. Day Break provides support through information programs, including a monthly newsletter called The Day Break Sun and through regular (or at least monthly) contact with Day Break staff about the care and functional needs of each member.

QUALITY OF SERVICE

According to the staff, Day Break is well known for its attention to the individual needs of each member and his/her families, and its high level of integration with the larger community and other service providers. In addition, it is recognized for its associated mental health services for members and its commitment to promotion of members' maximum functional independence. Day Break has a very low staff turnover (many staff persons are serving in their 13th and 14th years), ensuring stable and long-term relationships with members.

An outcomes research scale is under development. A key question: how to measure presumed reductions in caregiver stress level because of the support provided?

PROGRAM RESOURCES

Staffing: Six full-time activity/case managers, one registered nurse, and the program director.

Volunteers: Members of the Senior Services Community Advisory Council, student interns, activities and special event supporters, Senior Companions and approximately 30 students from a fifth grade class make monthly visits.

Funding: Includes grants for Day Break from the Alaska Commission on Aging and the United Way, agency social mission contributions, member fees, and Medicaid home- and community-based waivers. Member fees are established individually on a sliding scale. No one is denied service because of inability to pay.

PARTNERSHIPS

Day Break maintains close ties with other Anchorage senior service providers, including the Anchorage Senior Center and the Mabel T. Caverly Senior Center, home health and respite services, nutrition and transportation programs, and the local Alzheimer's Disease Resource Agency. These and other partners facilitate a strong, seamless support system for members and their families.

RECOGNITION

Day Break will be featured in an episode of the PBS series "The Visionaries" to air in 2001. PBS has highlighted only 64 nonprofit organizations over seven seasons, out of the more than 5,000 they have considered. Anchorage print

and broadcast media often features the center, and staff frequently speak at conferences and presentations. Comments from family members include: "Without Day Break I would not make it," and "I don't worry when my loved one is at Day Break."

FUTURE GOALS

To meet the needs of a rising number of persons needing care, Day Break is exploring ways to expand service hours into evenings and weekends, establish satellite programs, and offer more personal care services to members. Day Break leadership is also seeking to add services provided to those provided at Day Break II adult day center which serves assisted living residents.

ADDITIONAL INFORMATION

Contact: Ken Helander, Senior Services Director, Day Break Adult Day Center, 9210 Jupiter Drive, Anchorage, AK 99507, Phone 907 346-2234, Fax 907 346-2601,

E-mail: daybreak@Alaska.net

FAMILY CAREGIVER SUPPORT SERVICE

BIG STONE GAP, VIRGINIA

A family caregiver infrastructure assists caregivers in a tri-county, rural, mountainous Central Appalachia area of southwestern Virginia. The service includes: eight group respite centers, an in-home respite program, and other services such as a public transportation program operated by the parent organization.

SPONSORING ORGANIZATION

Mountain Empire Older Citizens, Inc. (MEOC), an area agency on aging and public transit provider, delivered its first service in 1974. Today, it provides a wide range of support and assistance to a growing elder population and others participating in its intergenerational programs. Its Family Caregiver Support Service provides both group and in-home respite. Such groups usually meet in donated space of buildings including churches, town halls, community centers, and health facilities. The program's comprehensiveness and flexibility are due in large part to an extensive network of ongoing partnerships, or an infrastructure designed to mobilize community resources around the needs of family caregivers.

ASSISTANCE PROVIDED

The infrastructure supporting MEOC's Family Caregiver Support Services includes eight group respite centers, five caregiver support groups (including two Alzheimer's groups), a Family Caregiver Resource Center providing written and video materials, an annual Alzheimer's seminar, and a quarterly newspaper. Free transportation is available through MEOC's fleet of 53 vehicles, primarily wheelchair-equipped buses of varying sizes. In addition to respite, caregivers may also receive case management, personal care and homemaker services, an emergency monitoring system, pharmacy assistance, home-delivered meals, insurance and pension counseling, and a home safety program.

Both regularly scheduled and special in-home respite care is central to the program. The Family Caregiver Support respite services are provided on a continuum for as many as possible including individuals without the ability to pay or those who can hire someone independently.

MEOC assists families wishing to privately employ a respite aide by maintaining a registry of local those looking for in-home employment. Families hire, supervise, and pay the aides, however MEOC assists with training them on caregiving issues.

MEOC addresses the growing regional need for trained geriatric aides in several ways. MEOC staff team-teaches a special course for high school students in cooperation with the local school system. Students receive a geriatric aide certificate for successful completion of the course. Free training is also provided several times per year by MEOC for all in the community wishing to enroll in a geriatric aide class. The State Medicaid Department approves all MEOC courses.

Approximately 700 caregivers are served each month.

QUALITY OF SERVICE

"Mountain Empire Older Citizens has developed a caregiver infrastructure with the goal of making it accessible, seamless, user friendly, comprehensive and culturally sensitive to people in its region. It could be considered a "Senior Center Without Walls." — MEOC statement.

Evaluation of service is ongoing, including in-home review of care plans every six months. Caregiver families assess the program in writing and informally at monthly support group meetings. Monthly nursing visits and quarterly geriatric aide training also measure quality.

PROGRAM RESOURCES

Staffing: 90 geriatric aides, 4 respite center managers, 12 drivers,
1.5 registered nurses, 1 case manager, 2 administrative staff,
.5 outreach worker.

Volunteers: 3 registered nurses, 40 helpers in respite centers,
5 insurance counselors.

Funding: Older Americans Act 20%; Medicaid 32 %;
Virginia General Assembly 31%; Brookdale Foundation 1%;
United Way 1%; local government 3%; local sources 10%;
client contributions 1%; and Title XX 1%.

PARTNERSHIPS

MEOC regards partnering as the key to all its efforts. Major partners are area hospitals, Parish Nursing Program, Center for Independent Living, area churches, Volunteer Interfaith Caregivers, local Disabilities Service Board, Retired and Senior Volunteer Program, local governments, Brookdale Foundation, and the Virginia Department for the Aging.

FUTURE GOALS

To increase the number of group respite centers, to increase the number of days that service is provided at group respite centers, to locate funding to serve in-home waiting lists, to fund one case manager to work solely with area family caregivers located out of service area, to expand Alzheimer's and Family Caregiver resource center, and to provide more hands-on training to family caregivers.

ADDITIONAL INFORMATION

Contact: Julia Trivett, Director of Family Support Services, Mountain Empire Older Citizens, Inc. P.O. Box 888, Big Stone Gap, VA 24219, Phone 540 523-4202, Fax 540 523-4208.

E-mail: jtrivett@meoc.org

INTERFAITH CAREPARTNERS

HOUSTON, TEXAS

Volunteer Teams, assisted by a central nonprofit agency, give comfort, respite and other assistance to caregivers throughout Houston. A key strength is that the team members are recruited from congregations to serve frail seniors and others in their congregation. If the needs of the congregation are met, team members then serve other frail seniors from the community.

SPONSORING ORGANIZATION

In 1985, the cofounders of Interfaith CarePartners, Dr. Earl Shelp and Dr. Ron Sunderland, began using the concept of Care Teams to provide in-home care and support to families attempting to cope with HIV/AIDS. Since then, Interfaith CarePartners has gradually extended its Care Team model to meet other needs, including those faced by caregivers of persons with Alzheimer's disease and other conditions affecting frail elderly. Interfaith CarePartners (its original name was The Foundation for Interfaith Research Ministry) maintains relationships with 75 Christian and Jewish congregations in the greater Houston area.

ASSISTANCE PROVIDED

Outreach to caregivers in need of respite support is greatly assisted by congregations that recruit lay team members to identify households that need help. Training to deal with specific conditions is part of the program's design. Interfaith CarePartners trains team members to provide individualized, hands-on care and support. The care can then meet the needs of the person or family receiving care. Care Team services may include companionship, meal preparation, transportation, homemaking, shopping assistance, emotional and spiritual support and respite for caregivers. Team members have noted that some caregivers opt to remain in the home with a volunteer simply to enjoy the opportunity for companionship.

The number of team members assigned to each family depends on the individual needs of the care recipients. The ratio of Care Team members to care partners (clients) is approximately 6:1; a team of 24 members is able to support four to five families. Care Team members visit in pairs. The program is not advertised. Instead, community awareness spreads by word of mouth and referrals of hospital discharge planners, social workers and the staff of home health agencies. Through these referrals, the teams are well utilized. This model enables teams to provide

in-home presence two or three days each week (more frequently if indicated), and to maintain this presence over time without exhausting the volunteers.

Houston area teams serve more than 125 families who care for persons with dementia, as well as hundreds of frail seniors with other needs unrelated to dementia. In 2000, more than 1,000 individuals and family units received in-home Care Team support for a total of more than 60,000 hours. Since 1986, the total of in-home Care Team hours of support is nearing 1,000,000.

QUALITY OF SERVICE

"Teams with a clear sense of purpose manifest a self-consciousness and vitality that enables team members to sustain their team as they work through the ups and downs of Care Team life, including recruitment of new members, keeping teams focused on their mission, and maintaining the support of their respective congregations." (Connections, a monthly newsletter for Interfaith CarePartners, Vol. 13, No. 1, May 2001).

PROGRAM RESOURCES

Staffing: Seven, full-time professionals work in Interfaith CarePartners headquarters, planning and delivering training, conducting monthly information exchange and supervisory sessions for each team, serving as a clearinghouse for research, and preparing a monthly team member newsletter that serves as a continuing education tool.

Volunteers: 1,500 Care Team members serve the Houston area.

Funding: Congregation and individual donors, corporate gifts, local and national foundations and government contracts (HIV/AIDS, area agency on aging). Fund-raising often attracts participants from government, the entertainment world, and local television.

PARTNERSHIPS

In addition to close linkages with congregations, Interfaith CarePartners works in cooperation with hospital discharge planners, home health care and social service agencies, the Alzheimer's Association and hospices.

RECOGNITION

In 1997, a President's Service Award sponsored by the Points of Light Foundation and the Corporation for National Service recognized the corporation's community service and national leadership. Dr. Norman Vincent Peale's Positive Thinking Foundation honored Dr. Shelp in 1992 with an America's Award. The Rosalynn Carter Caregiver of the Year Award went to corporation Vice President Ron Sunderland in 1997. The Washington-based Committee to Preserve Social Security and Medicare presented its first annual Outstanding Service to Seniors Award to Dr. Shelp and Dr. Sunderland in 1999.

FUTURE GOALS

Interfaith CarePartners plans to replicate the Care Team model in 15 or more communities in various states in the next two or three years. They also plan to complete a review of programs and identify factors that contribute to the building of strong teams.

ADDITIONAL INFORMATION

Contact: Earl L. Shelp, Ph.D., President, Interfaith CarePartners,
701 North Post Oak Road, Suite 330, Houston, TX 77024-3877,
Phone 713 682-5995, Fax 713 682-0639.

E-mail info@interfaith-carepartners.org.

Web page: www.interfaith-carepartners.org

APPENDIX ONE:

SOURCES OF INFORMATION TO SUPPORT CAREGIVERS

Benefits Check Up

www.BenefitsCheckUp.org is a free Web-based service of The National Council on the Aging that allows older Americans and their families to quickly and easily determine what federal and state benefits they qualify for and how to claim them.

Children of Aging Parents (CAPS)

Woodbourne Office Campus, Suite 302-A

1609 Woodbourne Road

Levittown, PA 19057-1511

1-800-227-7294 8 a.m.- 4 p.m. EST Monday-Friday 24 hour voice mail

Internet: www.caps4caregivers.org

National resource and referral, covers all aspects of aging issues.

ELDERCARE LOCATOR

1-800-677-1116

9 a.m.- 8 p.m. EST Monday-Friday

Telephone assistance by trained staff to find community assistance for seniors.

Directs caregivers, professionals and those needing help to the appropriate Area Agency on Aging (AAA). In a few states, the State Unit or Office on Aging serves as the AAA.

National Alliance for Caregiving (NAC)

4720 Montgomery Lane, Suite 642

Bethesda, MD 20814-3425

1-301-718-8444 9 a.m.- 5 p.m. EST Monday-Friday 24-hour voice mail

Internet: www.caregiving.org

Family Care Resource Connection sponsored through NAC provides a single point access for caregiver videos, books, audiotapes, training manuals, brochures and Web sites. All resources were reviewed for quality.

Internet: www.caregivers.org/content/fcrc.html

Family Caregiver Alliance

National Center on Caregiving

690 Marker Street, Suite 600

San Francisco, CA 94104

1-800-445-8106 9 a.m. - 5 p.m. PST Monday-Friday 24-hour voice mail

Internet: www.caregiver.org

Provides information and referral to caregiving families and professionals caring for caregivers.

APPENDIX TWO:

NCOA ISSUE BRIEF THE NATIONAL CAREGIVER SUPPORT PROGRAM

The National Caregiver Support Program, enacted into law as part of the Older Americans Act Amendments of 2000. Still in its formative stages and funded modestly, the program nevertheless testifies to the growing national conviction that family caregivers, including grandparents raising grandchildren, must be encouraged and supported in providing essential services.

BACKGROUND

During 2000, Congress created a new National Family Caregiver Support Program under the Older Americans Act. The program is intended to be a starting point in relieving the enormous physical and financial burdens facing our nation's caregivers, many who are attempting to keep their loved ones out of institutions. The program provides respite care, supportive services, counseling and training. Priority is given to older individuals and families with the greatest social and economic need. The program is funded at \$125 million. This translates to only about \$5 per caregiver – far below what America's 23 million caregiving families need.

NCOA POSITION

NCOA urges Congress to double the budget for the National Family Caregiver Support Program, to \$250 million.

RATIONALE

Millions of American families are experiencing enormous caregiving burdens. According to a 1997 survey by AARP and the National Alliance for Caregiving, 22.4 million households (almost one in four) are involved in helping to care for an individual 50 years old or older. Almost one-third of caregivers take care of two or more people. The average caregiver spends about 8 years providing care, with about one-third of caregivers providing care for 10 or more years.

According to a 1997 survey of caregivers of cognitively impaired adults by the Family Caregiver Alliance (FCA), the mean number of hours caregivers provided care was 73 hours per week (over 10 hours per day). Almost all caregivers incur financial costs to help the care recipient with expenses, most frequently with food, transportation, and medications. On average, caregivers spent a total of about \$20,000 in out-of-pocket expenses.

According to the FCA survey, 76 percent of caregivers needed respite care.

The lack of caregiver support is harming U.S. productivity – According to a MetLife study, the aggregate cost of caregiving in lost productivity to U.S. business may exceed \$29 billion per year. The FCA survey found that, of those caregivers who had been in the labor force, 18 percent had quit their jobs to give care; 42 percent reduced their work hours; and 58 percent showed clinically significant symptoms of depression.

Supporting caregivers reduces nursing home placement – According to a University of Michigan study, a person in need without a primary caregiver is almost five times more likely to be recommended for placement in a nursing home than a person with a caregiver.

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NOTES

