The National Alliance for Caregiving & MetLife Foundation

National Family Caregiving Awards
Caregiving Program Report
# Table of Contents

ACKNOWLEDGEMENTS ................................................................. 2

AWARD WINNERS BY LOCATION .................................................. 3

2006 NATIONAL FAMILY CAREGIVING AWARD WINNERS ................. 4

2007 NATIONAL FAMILY CAREGIVING AWARD WINNERS ................. 5

LESSONS LEARNED AND REPLICAATION STRATEGIES ...................... 6

CAREGIVER SUPPORT PROGRAMS

- **Eldercare Partners Caregiver Services** ........................................ 12
  Eldercare Partners, West St. Paul, Minnesota

- **Family Support Services** ....................................................... 18
  Mountain Empire Older Citizens, Inc., Big Stone Gap, Virginia

- **Space of Beauty–Journaling Program** ....................................... 24
  Southern Caregiver Resource Center, San Diego, California

- **Home Educator Program** ...................................................... 29
  Alzheimer’s Family Services of Greater Beaufort, Beaufort, South Carolina

CAREGIVER EDUCATION PROGRAMS

- **Strengthening the Delivery of Family Caregiver Education** ............ 33
  through Partnerships
  University of Wisconsin-Extension, Madison, Wisconsin

- **Caregiver Manual** .............................................................. 38
  Stroke of Hope Club, Inc., North Palm Beach, Florida

- **Asian American Dementia Care Network** ................................... 42
  Alzheimer’s Association, Los Angeles, California

- **Powerful Tools for Caregivers** ............................................. 46
  Legacy Caregiver Services, Portland, Oregon

- **JustCare: Family Caregiver Project** ....................................... 53
  The House of Justice–Bet Tzedek Legal Services, Los Angeles, California

- **Alzheimer’s Caregiver Series** ............................................... 56
  Montana State University Extension, Bozeman, Montana

TECHNOLOGY

- **Supporting Caregivers through Technology** ................................ 60
  Family Caregiver Alliance, San Francisco, California

- **Long-Term Care Choices** .................................................... 67
  MinnesotaHelp Network, Rochester, Minnesota

NATIONAL ALLIANCE FOR CAREGIVING MEMBER ORGANIZATIONS .......... 72
Acknowledgments
The National Alliance for Caregiving is grateful to MetLife Foundation for its generous support of the 2006 and 2007 National Family Caregiving Awards. MetLife Foundation’s commitment to family caregivers has made it possible to identify outstanding programs around the country that offer support to and educate the legions of family caregivers who provide the backbone of long-term care services in the United States.

The National Alliance for Caregiving is also grateful of the many service providers throughout the United States who participated in the National Family Caregiving Awards competitions. The Alliance is most appreciative of the time and energy invested in completing detailed applications that gave the reviewers a full appreciation for the important work to support family caregivers nationwide. The Alliance commends all applicants for their tremendous efforts in responding to the needs of caregivers in their communities through innovative and effective caregiving programs.

Background
Non-profit organizations from around the country applied for the awards in the categories of caregiver support, caregiver education, and technology, either as a small community (with a population of 100,000 or fewer) or a large community (100,001 or more). Their detailed applications addressed a battery of questions and were judged in the following categories: innovation, effectiveness or impact, basis in research, diversity, and potential for replication or adaptability. Many outstanding applications were received and many innovative and effective programs were identified.

This caregiving program report provides detailed information about the twelve programs that received National Family Caregiving Awards in 2006 and 2007. This report also describes how each of the awardees used their award money to advance their caregiving efforts. The program descriptions to follow can be used by other organizations and agencies to replicate these innovative programs that are truly making a difference in the lives of caregivers across the country.

The caregiving programs are presented in the following order: caregiver support, caregiver education, and technology. The program descriptions to follow were written by staff from the award winning programs and include information on the programs’ background and goals, partnerships, outreach, challenges and barriers, evaluation, lessons learned, and information on how to best replicate the programs.

The report begins with an analysis of the critical lessons learned and replication strategies for organizations and agencies interested in implementing one or more of the caregiving programs described in this report.
2006 National Family Caregiving Award Winners

**Caregiver Support**

*Eldercare Partners Caregiver Services*
Eldercare Partners  
West St. Paul, Minnesota

*Family Support Services*
Mountain Empire Older Citizens, Inc.  
Big Stone Gap, Virginia

**Caregiver Education**

*Strengthening the Delivery of Family Caregiver Education Through Partnerships*
University of Wisconsin-Extension  
Madison, Wisconsin

*Caregiver Manual*
Stroke of Hope Club, Inc.  
North Palm Beach, Florida

**Caregiver Education and Excellence in Alzheimer’s Caregiver Support Award**

*Asian American Dementia Care Network*
Alzheimer’s Association of Los Angeles, Riverside, and San Bernardino Counties  
Los Angeles, California

**Technology**

*Supporting Caregivers through Technology*
Family Caregiver Alliance  
San Francisco, California

**Honorable Mention Awards**

*Changing Places: Men Emerging as Caregivers*
Alzheimer’s Association, Mid-Missouri Chapter  
Columbia, Missouri

*Out of Home Respite Program*
Area Agency on Aging 1-B  
Southfield, Mississippi
2007 National Family Caregiving Award Winners

Caregiver Support

Space of Beauty—Journaling Program
Southern Caregiver Resource Center
San Diego, California

Home Educator Program
Alzheimer’s Family Services of Greater Beaufort
Beaufort, South Carolina

Caregiver Education

Powerful Tools for Caregivers
Legacy Caregiver Services
Portland, Oregon

JustCare: Family Caregiver Project
The House of Justice—Bet Tzedek Legal Services
Los Angeles, California

Caregiver Education and Excellence in Alzheimer’s Caregiver Support Award

Alzheimer’s Caregiver Series
Montana State University Extension
Bozeman, Montana

Technology

Long-Term Care Choices for Seniors, Caregivers & Families
MinnesotaHelp Network
Rochester, Minnesota

Honorable Mention Awards

Telephone Support Groups
Senior Services of Albany
Albany, New York

Drop-In Respite and Cooperative
Asian Community Center
Sacramento, California
Lessons Learned and Replication Strategies

The following section presents a summary and analysis of the most important lessons learned and replication strategies from the twelve National Alliance for Caregiving/MetLife Foundation National Family Caregiving Award winners from 2006 and 2007. This information can be used by agencies and organizations that are committed to implementing new programs to address the needs of caregivers in their communities. Detailed descriptions of the twelve programs follow this section.

Involve Caregivers in Program Development and Design: If an organization or agency is seriously considering developing new caregiver programs, a logical starting point would be to identify caregivers in the community and invite them to share their thoughts and ideas. This can be accomplished through focus groups, public hearings, or another approach, perhaps in conjunction with other organizations that will be involved in the caregiver programs. These events would be specifically designed to hear from family caregivers and identify what their needs are. Respite services, transportation, and refreshments for caregivers wishing to attend should be provided.

By listening to caregivers and acting on their input, organizations and agencies can establish an environment of trust that is critically important to the success of caregiver service programs. Without trust, caregiving programs will flounder and never really take hold. The necessity for meaningful involvement of caregivers in program development and design cannot be emphasized too much. Programs must be designed and retooled to meet real needs as identified by caregivers. Otherwise, efforts risk becoming guided by what best serves the organization and not by what best serves the caregivers themselves. Caregivers are the experts and this must be recognized and honored throughout program implementation and delivery.

Build Partnerships: Collaboration with other human service organizations is vital to successfully implementing and sustaining caregiver programs over time. Choose partners or key stakeholders wisely and involve those organizations that share similar values, such as the importance of supporting caregivers and operating as a team. A collaborative effort of several local agencies and organizations requires more planning initially, but has the distinct advantages of broader geographic coverage, combined marketing and funding efforts, and peer oversight to ensure quality control.

Whenever partnerships are developed, either with individuals or other organizations, the structure and expectations of the program and the various roles of the partners need to be defined explicitly each
Lessons Learned and Replication Strategies

time a partner is involved. Clear and direct communication by the program directors to all partners must take place on an ongoing basis with the timeline for completion and expectations made clear.

Unfortunately, not everyone knows how to play well with others and, as a result, these few entities and individuals can turn the best of plans toxic. Know your community and the players in it and involve those who bring positive energy to situations and who are guided by mission and not self-promotion.

Secure Adequate and Sustainable Resources: Because little public support is available to support caregiver service programs, organizations must be creative in seeking funding from national, state, and local funding sources. Funding must be sought not only for the start-up costs, but also for sustaining the program over time.

Obtain Support from Management and Other Departments: Implementation of caregiver service programs will require a commitment at the top management level with the recognition that family caregivers want and will benefit from such programs. In addition, management must be committed to provide adequate resources, both monetary and staffing. An organization must function as a team and avoid departmentalism and turf problems. Each department within the organization must absorb some costs, including costs related to actual provision of service and staff time. All staff must be flexible and willing to wear several hats at once.

It is also important for management and program staff to balance the need to accomplish program objectives with flexibility to respond to unanticipated opportunities and needs within a community that might arise during or after program implementation.

Create Effective Outreach Strategies to Diverse Communities and Rural Areas: The utilization of skillful outreach workers indigenous to a community and/or culture to promote the program is vital to the success in reaching out, especially to rural and underserved ethnic minorities. Outreach to multicultural communities requires a great deal of time. Long timelines need to be allowed in planning a project. For example, it often takes time to establish rapport within an ethnic community. Identifying key respected organizations or individuals within an ethnic community to help with outreach efforts and to offer programs for caregivers can greatly assist in establishing rapport. Traditional methods (e.g., printed brochures) may not be successful if used without personal contacts to
Lessons Learned and Replication Strategies

key organizations and individuals with those cultures with significant language, economic, and literacy barriers. Outreach strategies at all levels—upper management as well as grass roots—is important to reach out to underserved populations.

Creative strategies for support are needed to sustain a program in underserved rural and ethnic minority communities. Because these groups are struggling economically and may be overburdened in trying to meet a multitude of basic needs for their community, substantial barriers impede community organizations from supporting a new program. One approach to overcome this challenge is to create a support fund to address transportation, respite and day care for class leaders and caregivers.

Another successful approach to reaching rural caregivers is to take a program to the caregivers where they live. This approach may require repeating a program in different parts of a community, county, or state. Rural residents, who are frequently isolated, are able to network and meet others who are in the same situation when programs are brought to them. Also taking advantage of technology, such as web sites, on-line discussion or support groups, and videoconferences, is another method to reach rural caregivers.

Strive for Cultural Sensitivity and Appropriateness: Caregiver program content must be culturally appropriate for the underserved rural and ethnic communities they are intended to serve. As a result, programs will be well received by diverse ethnic communities when translated into their native language. In working with diverse ethnic groups, cultural assumptions of what would work and not work for a community should be challenged. Before offering a program such as a caregiver education class, the process of discussing the need to modify the curriculum is important, as is the consensus to pilot test the program without modification. Thus, it is recommended that other programs conducting outreach to ethnic communities consider first testing their program without modification to determine if it is culturally appropriate or not and then make modifications based upon the feedback received from participants, rather, than to first use input from focus groups to make changes in the curriculum prior to pilot testing.

Translation of program materials, such as brochures and educational handouts, involves much more than word for word translation and must include pilot testing and adequate time and resources for revisions as needed. It is important to have team members who are bicultural as well as bilingual for outreach, and to recognize that the intended target
Lessons Learned and Replication Strategies

Audience may have a great diversity of English and other language ability in speaking and reading due to where they were born, number of years in the U.S., and education level. This makes it difficult to develop one set of educational or support materials (or publicity) that will fit all needs. It is also important to consider the need for translation of the many program support materials for a monolingual minority community.

Require Staff Training: As talented and experienced as many social workers and geriatric professionals are, sometimes their academic and professional experience may not prepare them for some aspects of caregiver support and educational programming. For example, when working with diverse ethnic communities or with complex conditions such as Alzheimer’s disease, staff must be well trained, culturally competent, and prepared to serve these population groups and caregivers with unique needs.

If a program involves coaching caregivers—a significant skill in its own right—an initial training and periodic update sessions by a highly respected coaching trainer will help staff become grounded in coaching philosophy and techniques. Staff can then become increasingly confident in the efficacy of their coaching work and their ability to differentiate it from other interventions.

Evaluate Programs on an Ongoing Basis: Program evaluations should be conducted on an ongoing basis and may include caregiver satisfaction surveys, focus groups, and program evaluation surveys. For organizations with limited expertise and resources for evaluations, a recommendation is to partner with local colleges and universities that can assist with evaluation design, implementation, and analysis. Some organizations also have an “open door” policy that encourages caregivers to contact them at any time to discuss issues of concern and offer new ideas as a means to provide program improvement on a continual basis.

Create “One-Stop Shopping” Over Time: Over several years, agencies and organizations that are truly committed to meeting the needs of caregivers should plan to create a comprehensive set of services for caregivers and provide a “one-stop shopping” entity for accessing these services to meet caregiver needs. The goal of comprehensive services and “one-stop shopping” is to make services accessible, seamless, user-friendly, and less stressful to meet the diverse needs of caregivers in a community.

Don’t Increase Burden on Caregivers: Caregivers are so overwhelmed with the many roles they already play that they cannot be expected to develop something
on their own. The primary goal of caregiver support programs is to lessen the burdens and concerns of the caregiver, not to contribute to them by providing them another task they need to complete. For example, the Stoke of Hope Caregiver Manual Program utilized volunteers to create the manuals for caregivers instead of the caregivers having to do this task themselves. In addition, any caregiver education program should not require homework or hours of reading.

**Utilize Volunteers:** Volunteers are an excellent way to expand a program and serve more caregivers within a community. It is critical that all volunteers receive adequate training in whatever aspects of caregiving they will be involved. Clear and direct communication from program staff to all the volunteers must occur on an ongoing basis with timelines and expectations clearly articulated. In addition, program staff must nurture the caregivers over time and organize volunteer appreciation events or other ways to recognize the important contributions that volunteers make to a program’s success.

**Develop Programs That Are Not Dependent on One Staff Person:** A potential challenge for a new caregiver program in rural area is for the staff, especially if there is only one staff person, to feel as though they are the only ones who can provide the service to the caregivers. It places undue stress on the small staff, fosters and unhealthy dependence on the staff by the caregivers who may view the staff person as their personal counselor, and leaves the agency vulnerable in the case of the staff person’s absence. For this reason, it is valuable to have an assistant or alternate staff who are thoroughly trained.

**Develop a Marketing Plan:** An important lesson learned during the implementation phase of a new program is that the staff is inevitably involved in marketing. Staff must be comfortable with marketing the new program to all the local resources, particularly in handling a possible rejection from busy physicians, nurses, and others who may be referring caregivers to the program. It is vital for staff to not take rejection personally and to bounce back easily from disappointing first contact. Program staff must be prepared to address possible naysayers. Developing a marketing plan, in conjunction with partners, at the beginning of program implementation is critical to program success. A key component of the marketing plan is to develop approaches to identify persons who may not self-identify as caregivers. A possible approach would be to ask broad based questions when identifying caregivers, e.g., Do you assist someone with a disability? or do you care for someone with memory loss?
Try to Anticipate Program Participation: When planning a new caregiver program, it is important to factor in attrition in estimating numbers of program attendees. For example, a lower than anticipated class attendance or support program participation may be experienced when new programs are introduced. As a program becomes more established, more people will be aware of the program, and consequently attendance or participation may be greater than anticipated.

Technology: The following methods have been used successfully to reach caregivers who, for example, might not otherwise find general information about caregiving support, attend an educational program, or join a support group because of common caregiver challenges such as finding someone to come into the home while the caregiver attends a program.

Videoconferences: Generally across the U.S., investment in community videoconference technology infrastructure can be found in libraries, rural hospitals, health clinics, schools, distance learning centers, and county offices. These resources may be underutilized, depending on the community. Videoconference technology has the advantage of scalability to cover a local network, or regional or statewide capacity. It also offers interactivity depending on the number of sites involved. Costs vary widely for use of these facilities although some sites may not have a use charge for community programs.

Conference Calls: Conference call technology has the advantages of using an ubiquitous technology—the telephone—to deliver short (60 to 90 minutes) workshops. While this method usually requires an outside conference call service that can handle hundreds of callers, the price of this technology has decreased over time and the cost per minute has dropped to $.07/minute per caller recently. Both videoconferences and conference calls are great partnership or coalition building opportunities. They will not succeed unless there are a wide variety of partners who can contribute expertise to planning and conducting the programs, resources for marketing to their clients and the general community and potentially identifying locations and volunteers to assist with the program.

Web Sites: Recognizing the growing importance of the Internet and changing caregiving demographics towards more adult children, the Internet is an accessible vehicle for delivering practical content to caregivers. All community organizations should have a presence on the Internet with their own Web site. It is the way a majority of consumers will look for information in the community in the near
future and it offers wide marketing opportunities. All service agencies should have a site that clearly states their mission, services, eligibility, hours of service, fees, location, contact information (including email) and other information that could provide a full description of the organization.

**Discussion Groups:** On-line discussion groups are an excellent approach for caregivers to share ideas, get peer support and escape feelings of isolation so common when caring for someone with physical, sensory or cognitive impairments. E-mail list servs or blogs may be used to facilitate the caregiver discussion groups.

**Eldercare Partners Caregiver Services**

**Eldercare Partners**  
**West St. Paul, Minnesota**

This was a brand new idea to those who started it and is innovative now because of coaching and counseling, collaboration of multiple services’ agencies, and caregiver-directedness.

**Background & History**

Eldercare Partners is the service provision arm of the Strategic Alliance for Senior Services (SASS). SASS unites four of the most respected nonprofit organizations in the Minneapolis-St. Paul metropolitan area. The member organizations are geographically well-distributed and represent numerous points on the long-term care spectrum, including caregiver support, home health care, transportation, volunteer services, senior centers, housing, and more. The organizations all have deep community roots, having been in service from 32 to 106 years.

The first venture in 2000 was a market-rate care management service. In 2001 the local Area Agency on Aging convened focus groups of service providers and consumers to address how to reduce caregiver
strain and better support caregivers. They articulated what was missing: a one-to-one approach, connecting with someone who would get to know them and their situation and be there to call on throughout the twists and turns of their caregiving experience. It made sense for Eldercare Partners to help with systems development around these needs by augmenting members’ existing caregiver services with a program that would fill that void—a coach, a guide, a navigator for the caregiving journey. Eldercare Partners Caregiver Services was launched in 2002.

**Goals**

Through the Caregiver Services program, family consultants coach and counsel family caregivers so they have the information, skills, and life-balance tools to confidently provide care for as long as possible.

**Program Description**

Some caregivers simply have general questions about resources for themselves or the person they are caring for, and the family consultants advise them about community resources that will meet their needs. The heart of the program, though, is ongoing caregiver coaching and counseling.

The first step of this service, done in person, is a standard assessment of the caregiver: the caregiving tasks at hand, the caregiver’s own physical and mental health, the caregiver’s support system and family dynamics, legal

and financial responsibilities, and the rewards the caregiver is experiencing in the role. The caregiver assessment is a critical step in helping the caregiver focus on self rather than solely on the care receiver. When the program began, the Zarit Caregiver Burden scale was administered as part of the assessment, both to help reveal what some of the key stressors are and to create a baseline for comparison when the scale is again administered after a few months of coaching occurs. The program currently uses a wellness scale, which is believed to be more strengths-focused.

The caregiver and family consultant work together to set realistic goals. Goals might include involving other family members in providing care, learning how to handle memory loss and other difficult situations, or resolving to take time for one’s own enjoyment to prevent caregiver burnout. The family consultant uses coaching strategies and techniques to guide the way. Metaphor is one technique family consultants employ. For example, coaching is like helping a car mechanic work on the mechanisms of life—handing them tools and holding the light so they can see what needs to be done and have both hands free to do it. Other techniques include reframing to introduce new perspectives; asking powerful questions that cause reflection and get to the heart of the matter; and requesting or inviting the caregiver to stretch beyond self-imposed limits.
Caregiver Support Programs

The family consultant communicates with the caregiver on a periodic basis to offer ongoing support and direction, especially as new issues arise.

Applying coaching techniques to caregiver services was a new concept when the program began. A life coach was hired to train staff and serve as a mentor during the program start-up period. Unlike care coordination, education, or service planning, the coach is there to help the caregiver define reasonable, realistic, and attainable goals, to provide structure for making progress, and to support, validate, and nudge the caregiver forward.

The flexibility and affirmative nature of the service are also key innovations. After the initial assessment, the caregiver drives the process, selecting the frequency, method (whether in person at home or office, by telephone, or, increasingly, via e-mail), and focus of future contacts. Interaction with the family consultant may ebb and flow as goals are reached or revised, new caregiving challenges arise, or periods of calm are enjoyed. It’s somewhat trendy to have a career coach or a personal trainer to help you change and achieve goals. Capitalizing on the popularity of coaching and the positive association people have with it, the program innovators chose to apply that stigma-free and pathology-free approach to the world of caregiver support.

Program Partners

Amherst H. Wilder Foundation
Dakota Area Resources and Transportation for Seniors (DARTS)
Human Services Inc., Senior Community Services

Managers from each organization meet monthly to oversee program activities, implement quality assurance and staff training initiatives, and contribute to program development. Family consultants from all organizations meet together quarterly for ongoing training, case consultation, and policy and process review.

Program Evaluation

In mid-2004, Dr. Terry Lum of the University of Minnesota evaluated the effectiveness of Eldercare Partners Caregiver Services. Using a pre- and post-program longitudinal design to determine the program’s impact on caregiver burden, and a survey questionnaire and case record review to examine other effects, Lum measured caregiver burden, expected duration of caregiving, ability to provide care, and access to support services. This evaluation found that the service does reduce caregiving burden. The evaluation revealed the following:

- The first Zarit Caregiver Burden average score was 44 (indicating moderate to severe burden), and the average follow-up score was 39 (indicating mild to moderate burden), a statistically significant decrease.
91% of the caregivers believed the coaching helped them provide in-home care longer, with 50% stating it helped them provide care much longer.

75% of the caregivers reported that the services improved their communication skills with their care receivers.

95% said the services helped them cope with their caregiving role better or much better.

86% reported gains in insight into their caregiving role.

90% reported that the services helped them understand the importance of taking care of themselves.

83% of the caregivers reported that they were much more or somewhat more able to provide care after receiving the services.

In 2007, Eldercare Partners revised the intake, assessment, and goal-setting tools to enhance program effectiveness and align with a second program evaluation to be conducted in partnership with the University of Minnesota Family Caregiving Center. These enhancements include adding a depression screening tool, implementing a goal-attainment scaling process, and creating a moderated electronic list server for the family consultants.

This model’s applicability to diverse cultural and ethnic groups and to rural communities has been largely untested so far, but this is soon to change. One auxiliary feature of the service found to be especially useful to immigrant communities has been visits from a nurse, physical therapist, or occupational therapist to provide individual training or recommend adaptive equipment for specific caregiving situations. Tapping into the expertise of one member organization’s home care agency, Eldercare Partners makes these non-Medicare-eligible training visits available to clients of any agency in the [Twin Cities] Metropolitan Caregiver Network, a provider consortium initiated by SASS that now has 25 participating organizations. Group training for Hmong and Vietnamese caregivers has also been offered through this aspect of the program. Out of this connection has grown a more formal partnership with two organizations serving Southeast Asian and African families to bolster their caregiver services and to determine whether the coaching model suits those communities, or assess how to modify it to serve them well. Meanwhile, the Minnesota Department of Human Services (MNDHS) has engaged Eldercare Partners to develop a curriculum and train caregiver coaches statewide. The first of these trainings took place December 2006, to be followed by more in-depth practice application training in December 2007. Provided in five different locations across the state,
the training will reach practitioners from a wide variety of service settings in large and small cities and rural areas, thereby further exploring the potential applicability of the coaching model.

Lessons Learned
Whether replicated in a single agency setting, a multi-agency collaborative structure like ElderCare Partners, or even as a private practice, staff will require training in coaching techniques distinct from other skills. This is critical, and one of the most important lessons to date. As talented as the social workers and geriatric professionals were at the outset of the program, their academic and professional experience had not prepared them in the art of coaching, a significant skill in its own right. The initial training and periodic update sessions by a highly respected coach help staff become grounded in coaching philosophy and techniques. These skills are reinforced through quarterly family consultant meetings where peers share their successes and challenges, and at any time through the program’s virtual learning list server. As a result, the ElderCare Partners staff has become increasingly confident in the efficacy of their coaching work and their ability to differentiate it from other possible interventions. Although the staff has not pursued coaching credentialing, this too is an option. There are a number of coaching training programs and professional associations that could serve as a resource to emerging programs.

Replication
ElderCare Partners can provide additional information to aid program replication, including fee-based consultation on systems development, program evaluation, and collaborative best practices. ElderCare Partners would welcome joint venture interest/investment in creating a web-based training platform for caregiver coaching as well as a participatory online caregiver community.

This program is one of the first of its kind nationally. The collaborative nature of the service is one of its greatest strengths. By uniting the service menus, skill sets, and geographical reach of several organizations, ElderCare Partners can offer a level of expertise and an array of supports that is broader than any one agency could provide alone. Members use the same standards, definitions, policies, and procedures to ensure consistent high quality. The centralized intake function, staffed throughout business hours, streamlines program access and data collection. A call to one number from anywhere in this large metropolitan area connects the caregiver to a personal guide for their caregiving journey—a guide backed up by a multitude of related services. The program could be partially replicated (on a small or large scale) in a
Caregiver Support Programs

A single agency would have the appropriate training and procedures. A collaborative effort of several agencies requires more planning initially, but has the distinct advantages of broader geographic coverage, combined marketing and funding efforts, and peer oversight to ensure quality control. Since this was not the first service developed by the collaborative, much of the necessary infrastructure was already in place.

Eldercare Partners family consultants began with deep expertise in the fields of aging and caregiving, honed over years of direct practice in their respective organizations. The solid reputation of the practitioners and their organizations was a great asset for program promotion and acceptance. A similar experience base will be an important foundation for any new program.

How was the award money used?

Eldercare Partners initially designated the award money as part of a 50 percent match required to leverage grant funding from the Minnesota Department of Human Services. The proposed online project would have maximized outreach through a participatory caregiver web destination for the region. Since learning in July, 2007 that the proposal was not selected, staff has used $5,000 to secure a marketing firm to develop a comprehensive communications plan by year-end.

The plan will capitalize on recent accomplishments and recognition and will provide key messages for targeted audiences. The resulting tactical marketing plan will direct the staff to strategic application of the remaining funds beginning in 2008.

For more information

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Caregiver Support Programs

Family Support Services
Mountain Empire Older Citizens, Inc.
Big Stone Gap, Virginia

Facing the challenges of serving caregivers in a rural environment, these caregiver programs provide a broad array of support services to a large number of families.

Background & History
Located in the mountains of southwestern Virginia in the midst of Central Appalachia, Mountain Empire Older Citizens, Inc. (MEOC), a private non-profit corporation, is the designated area agency on aging, public transit entity and Children’s Advocacy Center for the Virginia Counties of Lee, Wise and Scott and the City of Norton. Established in 1974 with a small $12,500 planning grant, MEOC presently operates a $5.2 million budget using 87 different funding sources to provide 35 direct services to older individuals and their families.

MEOC’s mission statement states, in part, that it is committed to the prevention and unnecessary and/or inappropriate institutionalization of older persons by: developing and maintaining of comprehensive user-friendly community based long term care services; recognizing that families provide the bulk of care for older people and thus developing a user-friendly comprehensive infrastructure to support family caregivers; and serving as an active and responsible advocate on issues affecting older persons. MEOC is based on the strong belief that older people, if given the choice, prefer to live in their own homes in their own communities and not be placed unnecessarily and inappropriately in an institution. MEOC works to provide choices for caregivers. A community task force was organized by MEOC to address concerns of families caring for frail older relatives.

Program Goals
MEOC’s Family Caregiver Support Services address the needs of families caring for persons age 60 plus and the needs of relative caregivers with children 18 and younger. Since 1982, the agency has placed a major emphasis on services that support, encourage, empower and educate family caregivers. Since the program’s inception, thousands of family caregivers have received assistance and an average of two hundred caregivers receive respite assistance through the program monthly.

Program Description
The caregiver support infrastructure developed by MEOC includes ten community group respite centers,
Caregiver Support Programs

an in-home respite program, an overnight and emergency respite program, adult day health care, care coordination and nine caregiver support groups (including two Alzheimer’s groups, an online Alzheimer’s support group and four relative caregiver groups). A Family Caregiver Resource Center, an annual Alzheimer’s Seminar, caregiver education programs, a quarterly newspaper, pharmacy assistance, personal care, homemaker services, transportation and home safety program are additional services available to assist caregivers. The KinCare Program (relative caregivers) provides assistance annually with back to school supplies, monthly family social activities, case management, transportation and holidays for kids.

Each year MEOC serves over 2,500 family caregivers in its emergency, transportation, home delivered meals, care coordination, information and assistance and personal care services programs and through its support groups and educational offerings.

What is unique about MEOC’s Program for Family Caregivers is that it is not just a single service, but it is a comprehensive set of services intentionally developed over the years for the purpose of providing a one stop entity for caregivers to have access to an infrastructure of support services to meet their needs. Since the inception of MEOC’s program for caregivers, staff has remained focused on the goal of making it accessible, seamless, user-friendly, comprehensive and culturally sensitive to people in the region. All ongoing and proposed MEOC efforts are based on meeting the needs of family caregivers.

Using an Asset Based Community Development Model, MEOC remains focused on the strengths of the Central Appalachian area in solving problems. The glass is always seen as half-full, not half-empty. MEOC operates under the guiding philosophy that, “If the problems are within the community, the solutions are within the community.” MEOC organizes the community’s strengths, in partnership with private, state and federal resources, to address needs as expressed by the local community.

MEOC uses as its standard for cultural competency and diversity the following definition: the capacity to function in more than one culture, requiring the ability to appreciate, understand and interact with members of diverse populations within the local community. Written policies and procedures include a statement on non-discrimination; MEOC is an equal opportunity employer; provides training opportunities on diversity issues (ethnicity, gender, disabilities, sexual orientation, religion and culture); and makes provisions for non-English speaking persons. MEOC provides
Caregiver Support Programs

community outreach to traditionally underserved populations. MEOC staff finds that they must spend much time educating those outside of the region to the distinct culture of the Appalachian region. Staff also recommends that Appalachian people be included in diversity and cultural competency trainings offered elsewhere.

**Partners**
MEOC regards partnering as a key to all its efforts. Since its inception in 1974, the agency has realized the importance of developing close working relationships with other agencies and organizations. Key partners involved in caregiving efforts are: area hospitals, Parish Nursing Program, Center for Independent Living, AARP, Community Health Clinics, Senior Navigator, churches, Volunteer Interfaith Caregivers, local Disabilities Services Board, Retired and Senior Volunteer Program, local governments, civic clubs, Brookdale Foundation, Virginia Department for the Aging, and the Northeast Tennessee/Southwest Virginia Chapter of the Alzheimer’s Association. A key to the success of the caregivers’ programs is the ability to mobilize community resources around the needs of family caregivers and to organize the support of local, state and federal elected officials. MEOC puts primary emphasis on organizing community support and involvement in its programming. MEOC’s annual budget for Family Caregiver Support Services is $1.6 million (excluding transit).

Developing win-win partnerships with a host of others is very important, no matter the service, initiative or activity. For example, MEOC was able to offer top quality training for caregivers and professionals in the region because they have involved 20 other organizations and associations who each provide a small amount of funding which, when pooled, allows them to bring nationally and internationally respected speakers to the middle of Appalachia. MEOC is able to teach high school students to teach caregivers to use the Internet because they have partnered with the local school board, the Health Sciences Library outreach staff of a major university, the Alzheimer’s Association chapter, adult basic education program and the transit, case management and family support services departments of MEOC. MEOC has developed a technology manual and are developing a “Best Practices” manual that when available will guide in replicating caregiver programs elsewhere.

**Program Evaluation**
MEOC has grown from an area agency on aging offering basic Older Americans Act services to a multi-funded agency providing a wide array of services to caregivers and older individuals. These programs have been built over the years by: listening

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Know your community and the players in it and involve those who bring positive energy to situations and who are guided by mission and not self-promotion.
Caregiver Support Programs

and responding to the expressed needs of caregivers; locating and securing new funding sources; and developing strong, diverse partnerships. Since the inception of the National Family Caregiver Support Program of The Older Americans Act, many organizations now offer limited services to family caregivers. However, MEOC has always made the needs of caregivers central to all its efforts. All ongoing and proposed efforts are evaluated as to whether or not and how well they meet the needs of caregivers. The infrastructure of support services for caregivers has been built incrementally over a number of years. Thus, with national interest in support for caregivers reaching a tipping point, MEOC finds itself well positioned.

Evaluations of services are ongoing, including routine reviews of care plans, satisfaction surveys with all caregivers and an “open door” policy that encourages caregivers to contact MEOC at any time to discuss issues of concern and offer new ideas. Family caregiver surveys reveal that older family members do in fact avoid institutionalization because of MEOC’s services.

MEOC employs various means in soliciting caregiver input. Community needs assessments are completed annually with caregivers. Focus groups are held to discuss needed services and programs. Agency personnel serve on numerous advisory boards and committees of other agencies and organizations on both a local and state level. Community speak-outs are held at MEOC community centers to solicit concerns and ideas.

Lessons Learned

When MEOC began seriously to develop new programs for caregivers, MEOC held a series of five public hearings across the region, one in conjunction with the State Alzheimer’s Commission and one in partnership with the State Department for the Aging, specifically to hear from family caregivers. MEOC provided respite services and transportation for any caregiver wishing to attend and included lunch as a part of the activities. There was a great turnout and caregivers spoke movingly and emotionally of their loved ones and their situations. The major, overriding theme of each hearing was the need for regular, routine respite services. Thus, guided by the community to give the primary attention first to developing respite services, MEOC proceeded to do just that. By listening to caregivers and acting on their advice, MEOC established the environment of trust that is so important to MEOC’s success.

Whenever MEOC undertakes any initiative, they do it in partnership with others. MEOC’s advice is to choose partners wisely and involve
those organizations that share similar values and who understand partnerships and the concept of operating as a team. Unfortunately, not everyone knows how to play well with others and, as a result, these few entities and individuals can turn the best of plans toxic. Know your community and the players in it and involve those who bring positive energy to situations and who are guided by mission and not self-promotion.

MEOC has consciously sought funding from scores of national, state and local funding sources to provide the array of caregiver services they offer. MEOC would be happy to share all of their funding sources and amounts of funding with interested parties. They have become known as advocates for the needs of caregivers and work in concert with others to make this issue part of the public discussion. They always include the voices and faces of caregivers in all situations and never presume to speak as the expert. Caregivers are the experts and staff recognize and honor that. Establishing and maintaining the trust of caregivers is essential. Without it, caregiving programs will flounder and never really take hold.

**Replication**

To replicate what MEOC does, interested parties would need to examine what they are presently doing and decide if they would like to reconfigure their existing services to make them user friendly and useful to caregivers. This should be done in partnership with caregivers. A logical starting point would be to identify caregivers in the community and invite them to share their thoughts and ideas. The necessity for meaningful involvement of caregivers in program development and design cannot be emphasized too much. It is critical that programs be designed and retooled to meet real needs as identified by caregivers. Otherwise, efforts risk becoming guided by what best serves the organization and not by what best serves the public.

MEOC’s efforts could be replicated if an organization truly commits to this mission, functions as a team and avoids departmentalism and turf problems. Each agency department must absorb some costs, including costs related to actual provision of service and staff time. All staff must be flexible and willing to wear several hats at once. Present times are very conducive to retooling existing programs and services and developing new initiatives to serve caregivers.

MEOC welcomes the opportunity to share their experiences. The agency is committed to fully disclosing any and all information requested that would assist others in replicating and/or adapting MEOC’s caregiver support programs.
How was the award money used?

Mountain Empire Older Citizens has used a large portion of the $25,000 award money to provide respite services for additional caregivers. Some of the money was used in the new overnight and emergency respite program which assists caregiver who find themselves in emergency situations which require immediate attention, such as medical or family emergencies. Most of this respite is provided in the home. However, the agency has agreements with several area nursing facilities and assisted living providers who offer respite in a facility setting.

MEOC also has recently opened a new social model group respite program in the area. This program serves a dual purpose; it provides a safe, secure and stimulating environment for individuals with some form of dementia, while giving caregivers the opportunity for a break from the constant demands of caregiving responsibilities. A portion of the award money has been used for this new service.

A portion of the award money was used for a new project. The agency has recently begun a caregiver photography project. A photographer and a Mountain Empire Older Citizens staff person visit caregivers and care recipients in their homes or day program settings to take photographs of the two. Some of the photos are more formal in nature, while others capture the two sharing a story or a humorous moment. MEOC unveiled these 11 x 14 matted and framed photographs (a total of 12) at the agency’s Eighteenth Annual Alzheimer’s Seminar on November 9, 2007. MEOC displayed the photographs at different libraries during November, National Alzheimer’s Disease Awareness Month and National Family Caregivers Month, in order to raise awareness of caregiving and caregiving issues.

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Caregiver Support Programs

**Space of Beauty**

**Journaling Program**

Southern Caregiver Resource Center
San Diego, California

This innovative program brings volunteer artists together to create custom-made journals—each a piece of art— with unique prompts to help family caregivers find their voice by providing a safe place to jot down worries, passions, hopes, and new ideas.

**Background & History**

Southern Caregiver Resource Center (SCRC) endeavored to take an uplifting, new approach to reducing the dangerous risk factors of caregiving, such as emotional and physical isolation, loss of self-esteem, anger, fear, and guilt. In 2004, SCRC initiated a journaling program called *Space of Beauty*, which has made numerous positive changes in the daily lives of caregivers. This is no ordinary journaling program. Each journal is a piece of art created by a volunteer artist.

**Goals**

The primary goal of the *Space of Beauty* program is to allow caregivers a way to refocus their attention on themselves. Through journaling, specific issues may come to the surface that can be dealt with in an environment of safety, thus enabling caregivers to feel less stress and tension in their caregiving role.

James W. Pennebaker, Chair of the Department of Psychology from The University of Texas, has written more about journaling (expressive writing) than any psychologist to date. His most celebrated book on the subject is *Opening Up: The Healing Power of Expressing Emotions*. This book presents astonishing evidence that personal self-disclosure is not only good for our emotional health, but boosts our physical health as well.

He has conducted controlled clinical research that sheds new light on the powerful mind body connection. This book interweaves his findings with insightful case studies on secret-keeping, confession, and the hidden price of silence.

**Program Description**

Initially, the steps were developed on how to set up this program, and then artists were sought to participate in the program. The specific implementation steps are:

- Find volunteer artists. Some of the artists are also former caregivers who have first-hand knowledge of the caregiving journey.
- Identify how writing may be a useful tool for caregivers.
- Connect with caregivers. Caregivers receiving a journal.
Caregiver Support Programs

must first complete a formal assessment done by one of SCRC’s staff of Family Consultants—a professional staff that includes persons with Master’s Degrees in Social Work, Licensed Clinical Social Workers, a Doctorate in Psychology, and Marriage and Family Therapist—to determine whether or not it would be a useful therapeutic instrument for them. The Director of the Caregiver-to-Caregiver Network, in turn conducts an in-depth, one-on-one interview with the caregiver to gather specific information about them to incorporate into their unique journal. Questions asked include:

- What are their favorite colors, flowers or gemstone?
- What refreshes their spirit, or, “puts more air in their balloon?”
- What are they passionate about (past or present)?
- Create a mini family tree of their relatives, and also identify if they have a close or best friend and where they live.
- When or if they have time to read for pleasure, and what author or books they like. These questions are a way to pull out information about their interests that have often been left behind.
- What are their favorite quotes, spiritual messages (if appropriate), hymns, songs, poems and thoughts for the day they find inspiring or uplifting?
- If no one was looking, how would they like to celebrate their birthday? Or, if they could take a trip for a week, where would they go (if they didn’t have to worry about their loved one)?
- A difficult question to ask is, “If you allow yourself to think about the future, even for a moment, what are some of your hopes and dreams for yourself?”

Prepare ‘Profiles’ of caregivers for the artists. The profiles include the information listed above that is gathered with the caregiver.

Artists select a profile that speaks to them. The profiles are reviewed by each of the artists, and then selected by them based on something within the profile that strikes a familiar chord, such as a favorite color, a shared birthday or favorite quote, or who they are caring for may hold something in common with the artist.

Workshops are held where the artists gather to work on their journals, get ideas and tips from each other, and gather supplies. The journals are created both at these workshops and on the artists’ personal time.
Caregiver Support Programs

- Journals are presented to caregivers at a Tea Party. Artists and caregivers attend a Tea Party where each caregiver recipient is presented with his or her unique journal.

- “Steer With Your Pencil” class is taught. The Director conducts a class with all of the journal recipients on ways to make their journal a useful tool and a safe place to capture their thoughts and dreams.

Planning and implementation for the Space of Beauty program took five months from inception to startup. Development of the program steps, finding the volunteer artists, identifying caregivers and developing the questions to ask to create their profile takes approximately two months; interviewing a group of ten caregivers and developing their individual profile took approximately one month; hosting workshops where the artists select a profile, gather supplies and create the journals took approximately six weeks; planning and hosting the Tea Party where caregivers receive their completed journal took approximately 2 weeks. Once the program startup has been completed, an ongoing program takes approximately three months to complete one session of caregiver journals.

Outreach
Journal recipients must first complete a formal assessment done by one of SCRC’s staff of Family Consultants to determine whether or not it would be a useful therapeutic instrument for them. With high levels of stress and depression in caregivers, referrals are made swiftly to the director of the Caregiver-to-Caregiver Network, who in turn conducts an in-depth, one-on-one interview with the caregiver. The information is compiled, giving rich insight into cultural, racial, ethnic, gender, age and other characteristics that bring life and energy to their individual journal. Through this process, the staff are able to address the diversity that exists among the caregivers served by this program.

Challenges and Barriers
Several challenges were encountered during the course of the program, including:

- Acquiring profiles from ten different caregivers. In the role of a caregiver, many people are consumed by their responsibilities to their loved one, making it difficult to schedule time alone with them to create their unique profile. Quite often the appointment with a caregiver needs to be rescheduled more than once. Program staff recognizes and accept this as part of the process. In addition,
Caregiver Support Programs

many times caregivers find it very difficult to disclose their feelings. One of the most difficult questions to answer is “what gives you energy and what are you passionate about?” It can be unsettling to caregivers not to know the answer to such a fundamental question; however, often that question begins to open a door for them to get their true feelings out.

Another challenge is coordinating many artists, with varying levels of talent and time, to end up with completed journals.

Retaining the volunteer artists can also be a challenge. Program staff believes in having the volunteer artists “come and go” from the Space of Beauty program, rather than trying to keep them forever. Recruitment is an ongoing part of the Director’s job, as well as always looking at new ways to acknowledge their talent and time. SCRC has hosted Artist Appreciation events, and presented each of the artists with special gifts; for example, pins created in the form of a journal and embellished with beads and handmade thank you cards were given to the artists.

Program Evaluation
A survey was developed and sent out to caregivers who received a journal. Some of the findings are:

In response to: “In your role as caregiver, please rate how helpful the overall journaling program is to you,” 80% of the respondents replied that it was helpful.

In response to: “How well do you feel your journal captures your personality (favorite color, style)?” 83% of the respondents replied extremely well.

In response to: “Did you gain any new insights about yourself, in your caregiver role, during the journaling process?” 85% responded that they gained new insights about themselves with the majority identifying that they learned taking time for themselves was important so that they could continue to care for their loved one.

In response to: “Did you gain any new insights about yourself, not specific to your caregiver role, during the journaling process?” 65% responded that they had gained new insights about themselves outside of their caregiving role that helped them to see that they have a life separate from caregiving that they need to focus on.

In response to: “If you had the chance to do it again, would you participate in this program?” 83% replied yes.

In response to: “Do you think having a journal would be helpful to other caregivers, even people who think they’re not writers?” 94% replied that it would be helpful.
Caregiver Support Programs

In general, success of the program is measured primarily by whether or not caregivers are using their journals, and in so doing, have found journaling to be an effective tool that provides support to them in their role as a caregiver. The feedback and follow-up SCRC has received from caregivers so far has been very positive. Of those who received journals, 100 percent have reported to SCRC staff that they have found new coping skills as a result of their participation in the Space of Beauty program. Of the men and women who have received journals, 93 percent have written letters and emails to the SCRC staff. They have also written to the artists expressing their deep gratitude for a journal that is far beyond what they had dreamed. Some of the comments received from the journal recipients are:

A daughter caring for her mother wrote: “The artwork on each page with my favorite colors is so meaningful. It helps me write to become more in synch with myself and the journey. It acknowledges me as a caregiver and the critical role I play in my mother’s life.”

A husband caring for his wife wrote: “When I went to war as a young man, my father gave me a diary and said, ‘When you are lonely write.’ I feel so lonely taking care of my wife and I read about the journaling program in your newsletter and am grateful I contacted my social worker to ask if I could have one. It was the first tea party I have ever gone to but I liked learning more about the importance of not keeping so many things in. I’ve learned more about myself from writing on the different pages. I like the way the journal looks, looks like me.”

Lessons Learned

One lesson learned is that in working with artists, while a creative and free flowing experience, the structure and expectations of the program need to be defined explicitly each time a new session of journals is begun. Many times artists work with another artist to create one journal, and when this occurs, it is important that they work together in a partnership in order to create one cohesive journal that reflects the caregiver’s uniqueness. Clear and direct communication by the Director of the program to all the volunteer artists needs to take place on an ongoing basis with the timeline for completion and expectations for content verbalized so that completed journals are turned in at the end of the session.

Replication

Implementation of a similar program will require a commitment at the top management level, as well as available resources, both monetary and staffing, support staff to assist, and identifying that family caregivers want and can benefit from such a program. Development of new programs should originate from a need within the population served by the agency/organization.
Home Educator Program
Alzheimer’s Family Services of Greater Beaufort
Beaufort, South Carolina

This program for caregivers of persons with dementia excels in rising to the challenge of providing comprehensive support for a rapidly growing, racially diverse, rural retirement community.

Background & History
The Home Educator Program began in 2000 when Alzheimer’s Family Services of Greater Beaufort (AFSGB) recognized that there was a significant number of caregivers in the community who were unaware of AFSGB’s services and the services of other support agencies. Often the caregivers who did find the services spoke of being completely overwhelmed and frustrated by the lack of information on disease progression, respite resources, financial support, or caregiver networks. There was virtually no planning involved, as the Home Educator simply began to contact caregivers referred to her. The Home Educator staff person began to contact local hospitals, social service agencies and other aging and medical agencies to notify them that the

How will the award money be used?
Southern Caregiver Resource Center will use the award money to expand and grow the Space of Beauty program. SCRC will offer a three-part series on journaling to caregivers who want to refine their journaling skills. The award money will also be used to offer counseling to caregivers who, through their journaling experience, have identified issues that they would like to explore more deeply with the help of a therapist. Respite care will be offered to them as well to allow caregivers the ability to take advantage of the services offered by SCRC. The award money was used for the procurement of journaling supplies, as they are needed. Finally, the award money was used to subsidize the 100th Journal Celebration Tea Party in November 2007. This gathering celebrated the 100th journal created since the inception of the program, as well as all the volunteer artists who created them, and the caregiver recipients.

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Caregiver Support Programs

Home Educator Program’s services are available. Since that time, the program has continued to expand to meet the growing caregiving needs in Greater Beaufort.

Goals
The goal of the Home Educator Program is to make the caregiver’s life easier and to relieve some of the stress associated with this responsibility. The Home Educator program seeks to alleviate caregiver immediate and long-term stress by providing education on resources, referral to various appropriate agencies, and training on basic therapeutic activities that can be conducted at home if the caregiver so desires. Initial success is measured by self-reported decreased caregiver stress obtained through follow-up contact within weeks of initial contact. Long-term success rates are measured by caregiver use of one or more of the resources for which they have been referred. Long-term success rates for the program exceed 95 percent, with all caregivers reporting immediate positive response to the initial contact.

Program Description
The Home Educator Program process begins with a referral for a home visit to assess the need for services. Caregivers are given top priority as the Home Educator makes this visit and follows-up on a regular basis. Alzheimer’s disease information is reviewed, an application for services completed, and a medical report requested for the patient to register for one of the agency’s programs: the Social Day Program or In-home Respite. If appropriate, the Caregiver will visit the Support Group, Social Day Program, or the Maintain Your Brain Group. The Home Educator stays in close contact with the caregiver with weekly phone calls or a second meeting. This period is critical because of the emotional issues the caregiver is facing. Caregivers are free to telephone the Home Educator for consultation or conversation. A feeling of warmth and availability is extended to caregivers who are often lonely. A registry of caregivers is maintained with current status of their health and the care recipient’s status. The Home Educator also oversees the Caregiver Support Group and Maintain Your Brain Support Group. The Home Educator’s knowledge of the Beaufort community, the medical community, residential homes, and possession of good problem solving skills creates an effective network.

The Home Educator Program was created by the Home Educator staff person, and was implemented by the agency in 20 work hours as described below. Implementation began immediately upon approval by the Board of Directors.

In order to have an effective Home Educator Program, the following is needed:

1. A qualified Home Educator who possesses a thorough knowledge
Caregiver Support Programs

of Alzheimer’s disease, local area resources, state and federal resources, and an understanding of the regional culture. Contact with the local, state, and federal resources, including a good working relationship with medically relevant personnel in the community is vital. The Home Educator was employed with AFSGB at the time and met these qualifications, which reduced a potentially three month hiring timeline to two hours.

2. Development of the funding proposal for the program (approximately 15 hours).

3. Presentation of the proposal to the agency Board of Directors to approve the program and funding (approximately 1 hour).

4. Initial referrals to the agency of caregivers in need of support (approximately 2 hours).

Collaborators

- United Way of the Lowcountry, South Carolina
- Local churches
- Aging network and community services’ organizations
- Alzheimer’s Association
- Local medical agencies

Outreach

Caregivers are self-referred, referred by other caregivers, family and friends, churches, hospitals, medical centers, aging agencies or by those who have seen program advertisements and brochures. Caregiver identification most frequently comes through the medical community, aging agencies, and other caregivers.

Challenges and Barriers

The biggest challenges to the Home Educator program were the racial and location barriers. In a southeast culture that still observes an unwritten racial code, the greatest triumph the Home Educator had in breaking these barriers was by contacting the local churches to present the program. By using these churches as a reference, caregivers began to accept an integrated program designed for them and their loved ones. The challenge of location was easily resolved by explaining to the caregivers that the Home Educator would visit them in their own homes, instead of making the caregiver drive to the Home Educator.

Program Evaluation

The Home Educator program has never been officially evaluated. However, staff does track the numbers of caregivers contacted by the Home Educator, and the number of clients who have subsequently received support from AFSGB or other agencies. In 2006, the Home Educator provided consultation and respite placement services to 79 families, 58 first referral home visits, and 130 follow-up visits. All of the current Social Day clients and In-Home Respite clients have come
Caregiver Support Programs

from an initial Home Educator visit. In 2008, staff will be conducting a statistical analysis of data from the Home Educator records to review where the caregivers have received the greatest benefit and how staff can better serve them.

Lessons Learned
The primary lesson learned during the implementation phase is that the Home Educator staff person is heavily involved in marketing. The Home Educator must be comfortable with marketing the agency to all the local resources, particularly in handling an initially brusque rejection from busy medical executives. It is vital for the Home Educator to be someone who does not take rejection personally and can bounce back easily from a disappointing first contact.

The greatest trap is for the Home Educator to feel as though they are the only one who can provide this service to the caregivers. It places undue stress on the Home Educator, fosters an unhealthy dependence on the Home Educator by the caregivers who frequently see the Home Educator as their personal counselor, and leaves the agency vulnerable in the case of the Home Educator’s emergency absence. For this reason, it is so valuable to have a Home Educator assistant or alternate who is as thoroughly trained in the community resources available.

Replication
The Home Educator Program is easily replicable. The key elements are a dedicated staff person with good communication skills, empathy for the effect of Alzheimer’s disease on the family, and knowledge of the services available in the agency and community. The financial cost of the Home Educator depends primarily on how little or how much the Home Educator requires in salary.

How will the award money be used?
The award money is being designated to cover the costs of the In-Home Respite that is not met by the fees. The In-Home Respite fees cover approximately 50% of the expenses incurred by providing quality Respite Aides and Respite Aide Manager. Average fees of for-profit agencies are $20.00 per hour. Our fees are $25.00 per four hours, or $6.25 per hour. The In-Home Respite program has a growing number of clients applying for services, and the award money will allow us to keep our fees at far below the average price. This in turn will allow us to redirect the money saved from the operating funds to the Home Educator Program.

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Strengthening the Delivery of Family Caregiver Education through Partnerships
University of Wisconsin-Extension
Madison, Wisconsin

The Alliance demonstrates the significant impact a coalition of organizations can have in serving family caregivers, an outstanding example of a statewide effort.

Background & History
The Wisconsin Alliance for Family Caregiving grew out of the success of teaching the curriculum, Powerful Tools for Caregivers, seven years ago. Caregiving professionals saw the value in creating a single organization that could provide statewide education to family caregivers. As a result, a core of committed individuals created the Alliance as a way to educate and support organizations and individuals working with family caregivers.

Goals
The Alliance’s long-term vision is for every family caregiver to receive the support and education they need to maintain their health and well-being. To accomplish that, the Alliance works to: make it easy for caregiving organizations to network; give educators the tools they need to support and educate family caregivers; and boost the overall level of family caregiving education in the state of Wisconsin through professional development. The Alliance measures its success through detailed evaluations of the caregiving curricula, statewide listening sessions, and direct feedback from caregivers, class trainers and others.

Program Description
The Alliance educates professionals who work directly with family caregivers. The Alliance is not a professional organization for paid caregivers. The Alliance has a statewide network of advanced instructors, or master trainers, who train individuals as class leaders in four caregiving curricula. Class leaders go on to conduct classes for family caregivers throughout the state. The Alliance also offers caregiving resources on its website (fact sheets, newsletters, publications and web links to state and national organizations); supports local caregiving coalitions; and creates networking opportunities. The Alliance has trained some 400 individuals—educators, social workers, health-care providers, aging-network professionals and others—as class leaders in one

Caregiver Education Programs
Caregiver Education Programs

or more of four curricula. Class leaders have, in turn, reached more than 2,000 Wisconsin family caregivers through workshops, consultations, support groups and other activities.

The web site: www.uwex.edu/ces/flp/caregiving/index.cfm shows Wisconsin family caregivers how to find caregiving classes around the state AND supports class leaders and master trainers with evaluations, marketing tools and teaching tips. The site also offers a wealth of resources for family caregivers.

To see the step-by-step process of the Alliance’s planning and development, visit: www.uwex.edu/ces/flp/caregiving/alliance/accomplishments/. The Alliance’s experience has been that it takes at least a year after providing curriculum training before class leaders actively use the new curriculum in their community. Throughout the development process, the Alliance has had some form of an advisory group to provide oversight. In the beginning, steering committee members were the worker bees. A part-time staff member allowed board members to step back a bit from the daily operations of the Alliance.

Program Partners

- Wisconsin’s family caregivers
- Wisconsin’s Area Agencies on Aging
- Wisconsin Aging Network
- University of Wisconsin-Extension
- The Hope of Wisconsin
- Wisconsin Respite Association
- The Alzheimer’s Chapter Network
- physicians and hospitals
- Wisconsin Bureau of Aging and Long Term Care Resources.
- 75-plus member organizations, representing a diverse network of professionals; other caregiving organizations, alliances and coalitions

The Alliance acknowledges its partners on their web site at: www.uwex.edu/ces/flp/caregiving/alliance/organizations/.

Outreach

The Alliance uses list-serves, web sites, displays, news releases, word of mouth, and other means to reach out to Wisconsin caregivers and caregivers across the nation. The Alliance uses a statewide list-serve called Badger to promote upcoming training. Also, each Alliance curriculum has a list-serve, as well as a friends’ list, with individuals receiving updates on Alliance training and activities.

The MetLife Foundation award
and AARP allowed the Alliance to create portable table-top exhibits, complete with banners, posters and promotional flyers. These exhibits go on display at caregiver conferences and professional development meetings around the state. The Alliance is in the process of creating a web page showing educators how to access and use the exhibits.

In 2005 the Alliance held 12 listening sessions throughout Wisconsin to promote the organization and learn how to fill statewide gaps in education, resources and support for family caregivers. Caregiving professionals identified six major concerns. Issues included family caregivers not identifying themselves as caregivers and thus not participating in educational programs, and caregivers’ reluctance to accept help. The Alliance used the data gathered during these listening sessions to develop a strategic plan to meet the educational needs of family caregivers throughout Wisconsin. The executive summary and full report can be found at: http://www.uwex.edu/ces/flp/caregiving/alliance/news/

To boost the Alliance’s ability to reach Wisconsin caregivers, they expanded and strengthened four educational task forces. The chairs of these task forces serve on the Alliance’s steering committee and have added responsibility; they offer training, nurture class leaders, maintain their section of the web site, and conduct evaluations.

**Challenges and Barriers**

The Alliance, like other nonprofits, is trying to sustain itself with scarce national, state and local resources amid a culture that does not appreciate the value of family caregivers. Caregivers are viewed as the “servant” of the long-term care system, with few resources. What help is available often doesn’t value caregiver education. The Alliance continues to look for ways to educate policy makers on the importance of keeping family caregivers physically and mentally able to care for family members so they don’t end up in the long-term care system.

In addition to resources, another challenge is assessing the statewide impact of Alliance training programs on family caregivers. Since the Alliance doesn’t have direct access to family caregivers, they must rely on class leaders to follow through with the evaluation process.

Leadership is an ongoing issue, especially within the past year, as two previous presidents had to resign due to job demands.
Caregiver Education Programs

and retirement. With the appointment of a new president and new board members, the Alliance will move forward with the strategic plan.

Program Evaluation
Evaluation has been crucial to the Alliance’s development and has been accomplished in several ways, including the steering committee collaboration evaluation. In 2004, steering committee members evaluated their work as a collaborative organization. The full report is available at: http://www.uwex.edu/ces/flp/caregiving/collaborations/resources/index.cfm

Curriculum Evaluations: Each curriculum has been evaluated to determine how it is being used and to gain insights into how caregivers benefit.

Powerful Tools for Caregiving: This curriculum has a pre- and post-survey that caregivers complete. Results are available by class or statewide. To review evaluation data, visit: http://www.uwex.edu/ces/flp/caregiving/education/powerfultools/evaluationresults.cfm.

Caregiving Relationships: Due to this curriculum’s many uses, two evaluations were sent to class leaders, asking them how they used the curriculum and to provide anecdotal information on how it benefited family caregivers.

Caregiving Near Life’s End: This curriculum relies on class leaders to create lessons, which has been difficult for some class leaders. Two surveys were sent to class leaders, requesting information on how they used the curriculum and suggestions on how future training should be conducted.

Elder Care and Work: This is the Alliance’s newest curriculum, with only one completed survey of class leaders. The emphasis is on how class leaders connect with business owners and employed caregivers.

Lessons Learned
The following lessons have been learned from seven years of creating, nurturing and sustaining the Wisconsin Alliance for Family Caregiving:

- A group of passionate individuals is needed to fashion a vision for how the organization can meet the needs of family caregivers.
- For maximum impact, every family caregiver in Wisconsin should have access to consistent, high-level caregiver education. This requires geographically distant organizations to work together and synchronize
Caregiver Education Programs

Vital to the Alliance’s success have been partnerships with family caregiver coalitions and organizations that provide services to family caregivers around the state. During the past six years, the Alliance has learned to persevere despite obstacles, to build on its successes and to constantly evaluate the impact of its educational programs. Some ideas that may be helpful for those who want to replicate the Alliance include:

- Build on existing structures in your community, region or state.
- Become a nonprofit, a structure that allows everyone to contribute to a new entity that is owned by all, and also reduces turf battles.
- Find ways to use and build on the expertise of member organizations.
- Find objective, outside consultants to help your group work through strategic planning, vision and mission development.
- Develop a source of funding for staff and out-of-pocket expenses.
- Start with a group of committed individuals to fashion a vision for how to meet the educational needs of family caregivers.
- Having a web site (http://www.uwex.edu/ces/flp/caregiving/index.cfm) gives class leaders support in teaching the

Replication

Replicating an organization such as the Wisconsin Alliance for Family Caregiving requires a committed core of individuals who believe that by working together they can create something that none could create alone.
Caregiver Education Programs

various curricula and is one of the organization’s key communication tools. The Alliance’s site offers teaching materials for class leaders and master trainers; names of state and national caregiving organizations; caregiving reading; caregiving demographics; and statewide posting of family caregiving classes and conferences.

For those interested in replicating the Alliance, the Alliance’s board members are more than willing to share experiences, expertise and advice.

**How was the award money used?**
The Alliance used some of the award money to pay for promotional packets. Some will go to administrative costs. However, the board is still determining how to use the award, with current discussions centering on using the resources as “match” in a grant application to secure an executive director.

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Caregiver Manual
Stroke of Hope Club, Inc.
North Palm Beach, Florida

_This all-volunteer group has developed an essential response to a universal problem for those caring for a loved one who has experienced a stroke._

**Background & History**
The Stroke of Hope Club, Inc., a not-for-profit organization, was founded in 1984. The mission of the Stroke of Hope Club, Inc. is to work toward increased awareness of stroke prevention, community education and to provide information to individuals and families affected by stroke. Stroke of Hope Club, Inc. provides services to all stroke “victors” and their families and friends, recognizing that no two strokes are the same and no two families coping with stroke do so in the same way.

The Stroke of Hope Club, Inc. began by offering monthly support group meetings for stroke “victors” and their families. From the first meeting, the meetings offered information in general, and also an opportunity for caregivers to meet separately from stroke “victors” in order to gain the support they so desperately need. Since 1984, the organization has seen incredible growth. What has
remained unchanged is that there are no dues or fees charged for the organization’s programs, although donations are accepted, and that volunteers are relied upon for over 95% of the programs and services.

**Goals**
The purpose of the Caregiver Manual is to provide the guidance and information necessary for someone else to step in and take over for an individual caregiver. The Caregiver Manual is a program unique to the Stroke of Hope Club, Inc. It was developed in response to the needs of our caregivers, and no doubt enhances their quality of life. Caregivers report that by having someone help them record all of this necessary information, some of the daily stress and frustration is lifted. In addition, the long-term worry of “what happens if something happens to me?” is reduced as a result of the Manual.

**Program Description**
The Caregiver Manual is developed and printed while a caregiver and “victor” meet with a caregiver education volunteer. The program was created by direct contact and reporting from caregivers themselves. Through the many caregiver support groups held since 1984, the overwhelming concern of “what if” and “who would take my place” and “how would they know what to do” became a constant theme. This program grew out of a caregiver’s simple statement, “I wish I had a book of all the information my daughter would need to do my job”. This was all the research that was necessary.

Information is typed directly onto the computer templates as each section is reviewed. The information is then printed, placed in protective plastic sheets and then these sheets are placed in a three-ring notebook. The Caregiver Manual is made up of seven sections:

1. **Primary Information:** This section contains all pertinent personal information: social security number, legal names and address, insurance information, physician information, and other items identified through discussion with the caregiver and stroke victor. Copies are made of all insurance cards and placed in the Manual.

2. **Medications:** A list of all medications, dosages, and how to administer these medications is prepared. This information is typed directly onto the “medications template.”

3. **Therapies, Social Activities and other Resources:**
   This section contains all contact information and scheduling information for: occupational therapy, speech therapy, physical therapy, Stroke of Hope Classes, hairdressers (manicure, etc), exercise programs, church/temple services, other.

4. **Phone Book:** This section includes all emergency contacts and physician information, immediate family contact
Caregiver Education Programs

information, professional advisors (therapy, etc.), and general phone book (friends, distant family).

5. Hurricane/Disaster Preparations: Needs are listed and plans are outlined.

6. Wishes/Advanced Directives: This section contains copies of each of the following documents: Living Will, DNR, Health Care Surrogate, Power of Attorney, Funeral Arrangements, Other.

7. Designs: This is where the volunteers discuss with each caregiver what we may have overlooked, what is important to them.

Each caregiver and victor is encouraged to inform their family as to what this Manual looks like, how and when to use it, and where it can be found in the home. Caregivers and victors are encouraged to meet with the caregiver education volunteer quarterly to update the information.

The Caregiver Manual program was first introduced in 2004. Staff has met with over 50 caregivers of stroke “victors” within our community. There is no limit as to the population of caregivers this Manual can serve. Any caregiver will benefit from taking the time to meet one-on-one with a caregiver education volunteer to develop their own Manual.

Evaluation

Each caregiver in the organization has been invited to meet and create a manual with our volunteers. Quarterly follow-ups have been offered to each caregiver. Thirty caregivers have participated in this program from within the organization. Effectiveness/impact has best been demonstrated through the on-going requests from other individuals or groups for assistance in developing their Caregiver Manual.

Replication

The Caregiver Manual program as developed by the Stroke of Hope Club, Inc. can easily be replicated and adapted. The Caregiver Manual is NOT specific to the population of stroke “victors” and caregivers. It is readily apparent to all that have used this Manual that it can provide great comfort and peace of mind to any and all caregivers. In the past six months, individuals have shared their Manuals with family members living in Michigan, Georgia and throughout Florida, assisting them in the development of their Manual. These other family members have experienced a variety of medical conditions and have come to greatly value having all of their medical and family information in one location. It is the intention and the hope of the individuals directly responsible for the development of the Caregiver Manual program that the

Partners

- Stroke of Hope Caregiver Education volunteers
- Caregivers
- Stroke victors
program be replicated in its entirety, not just the Manual itself.

The success of the Caregiver Manual Program is first and foremost a result of the one-on-one communication between the caregiver, victor and the caregiver education volunteer. Any organization wishing to replicate this program must be cautioned, however, that development of the Manual with a trained caregiver education volunteer is imperative to the success of the Caregiver Manual Program. It has been our experience that caregivers are too overwhelmed with the many roles they already provide to be expected to develop their Manual on their own. The primary goal of the Caregiver Manual program is to lessen the burdens and concerns of the caregiver, not to contribute to them by providing them another task they need to complete. Through the one-on-one communication with a caregiver education volunteer, we are often able to identify needs of the caregiver that may be met by community services they have not yet obtained. Stroke of Hope staff can refer caregivers to counseling services, respite or caregiver training offered through our offices.

The volunteers who developed this program for the Stroke of Hope Club, Inc. will provide all the details necessary to allow other organizations to adapt or replicate the Caregiver Manual Program. Interested individuals may contact the Stroke of Hope Club, Inc. by telephone: 561-745-0400 or by email: info@strokeofhope.org Label your request “Caregiver Manual Program Development” and one of the volunteers directly involved in the development and implementation of this program will respond to your request. Samples of templates used to create the various sections within the Manual are available at our website: www.strokeofhope.org. Go to the “caregivers” link. Outlines of in-service training of volunteers for the caregiver education program can also be shared with interested organizations.

**How was the award money used?**

The Board of Directors of the Stroke of Hope Club, Inc. decided that the award money should be used to further caregiver programs through the organization. Examples of how these funds have already been spent in 2007 include the following: purchase of Caregiver Manual materials and a laptop computer for our volunteer Caregiver Educators to use in visits with caregivers offsite and caregiver counseling for couples 59 years of age and younger.

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Caregiver Education Programs

Asian American Dementia Care Network
Alzheimer’s Association of Los Angeles, Riverside, and San Bernardino Counties
Los Angeles, California

This effective inter-organization collaborative model extends to multiple American-Asian communities and provides concrete assistance with dementia care.

Background & History
The Alzheimer’s Association’s mission is to eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for diverse populations with dementia, their families and caregivers; and to reduce the risk of dementia through the promotion of brain health. The overall goal of the Alzheimer’s Association in Los Angeles is to meet the needs of an ethnically and culturally diverse population by developing and testing innovative models of service delivery for at-risk and under-served populations with Alzheimer’s and related dementias.

Goals
The goals of a Dementia Care Network are to: (1) Establish linkages and build trust between local community organizations and the Alzheimer’s Association; (2) Assess community needs and barriers to service delivery; (3) Implement linguistically and culturally appropriate community outreach and education to reach caregiving families; (4) Facilitate access to existing services; (5) Facilitate program development and expansion; and (6) Evaluate existing translated information, develop linguistically and culturally appropriate materials, and disseminate them to the community through provider networks.

Program Description
The Asian American Dementia Care Network builds upon inter-organizational collaboration to develop and provide dementia care services in under-served ethnic communities. The Network brings together nonprofits, community stakeholders, and government entities to problem solve together in order to fulfill community needs in a culturally acceptable manner.

In July 2000 the Asian American Dementia Care Network began targeting Chinese and Japanese family caregivers in Los Angeles and Chinese and Vietnamese families in San Jose, California. Later, the project expanded to include the Chinese community in San Francisco and the Korean community in Los Angeles. Over 500 family caregivers have received hands on assistance, and over 8,000 have benefited from linguistically matched education.
Caregiver Education Programs

Program Partners
- Nonprofit human services providers
- Program consumers
- Community representatives
- Government entities.

The strength of the project is the collaboration among agencies. These partnerships result in the collective ability to develop and offer culturally competent programs, and, it results in the partner agencies institutionalizing their newly acquired dementia capacity in the services they offer to the community. Examples of this type of collaboration include translation of materials, joint education presentations, and, cross training of staff on issues of dementia and cultural competency.

Outreach
One of the Care Advocate’s roles is to conduct outreach into the community through traditional locations like churches, senior centers, social service and medical agencies, and to identify non-traditional locations for outreach in the targeted community such as ethnic markets and cultural festivals.

Program Evaluation
Based on data collected through El Portal (the Latino Alzheimer’s Project), the Administration of Aging deemed the Dementia Care Network as an evidence-based model that effectively reaches, serves, and

about memory loss and Alzheimer’s disease. In addition, direct caregiver support activities that have been most used include respite care funds; support groups (six new groups established and conducted in Japanese, Chinese, Vietnamese and Korean); and caregiver training.

The Alzheimer’s Association’s role is to work with members of the Dementia Care Network to complete a needs assessment, to train partner agency staff in issues around dementia, to translate and print materials, to process respite reimbursements and to collect program evaluation data. Although there are clear roles and responsibilities by different parties, the work is conducted and implemented jointly. Additionally, a community advisory board serves as an oversight committee, providing guidance and expertise in delivering appropriate services and programs.

The Dementia Care Network addresses cultural barriers by:
- Increasing awareness of the disease through outreach and the ethnic media
- Creating culturally and linguistically appropriate literature
- Offering Care Advocates
- Providing support groups in the language of choice
- Helping families with their respite expenses.
Caregiver Education Programs

provides quality programming for ethnically diverse families impacted by dementia. This evaluation revealed that the model led to a significant increase in service utilization by a community that historically underutilized existing programs. During 2002, nine focus groups were conducted in Chinese, Vietnamese and Japanese, in both Los Angeles and San Jose, to determine attitudes towards Alzheimer’s disease, challenges faced by Asian caregivers, and recommendations for promoting culturally sensitive dementia care. The focus group data had a strong influence on terminology and literature used for the project.

In addition, through more informal mechanisms, staff monitor frequency of use and types of services, evaluate consumer satisfaction and assess the progress made addressing gaps in service.

Lessons Learned

The lessons learned from this project are varied and include the following:

- Utilize key community stakeholders or an advisory group. These individuals provide instant credibility and assist in navigating the target community and cultural norms.

- Maintain consistency, flexibility and an on-going commitment to serve the target community. The experience is that the Alzheimer’s Association’s consistent presence in the community over time, sometimes even years, allowed the community to build trust and understand services offered.

- Mentoring care advocates. These individuals are the heart of the project and the greatest advocates for the families. As these care advocates acquire new skills and knowledge, they grow into progressively more responsible positions. Within these new positions, they have the ability to continue to build the dementia capacity of their agency and their community.

- Allow time for “visible” results. Objectives around building trust and increasing awareness are difficult to measure. Frequently, it takes time to recruit clients and provide respite.

- Modify concept of the caregiver. Traditional thinking focuses on a primary caregiver. Our experience with these Asian communities is that the caregiver consists of the family unit with different family members responsible for different responsibilities.

- Standardize a translation protocol to ensure a high quality of materials. Poor translation can distance those whom you are trying to attract. Additionally, an array of materials is beneficial as families are in need of information.
Replication

The Dementia Care Network was developed for and replicated in diverse communities. In fact, this model has never been replicated in a mainstream community. The Asian American population is a diverse group within itself. This model tailors the program and services to the specific needs and cultural values of each target community.

The Dementia Care Network is a model that has been successfully implemented in a total of six Asian American communities, as well as in Latino and African American communities in California. While each community had its own existing formal and informal network of agencies; cultural beliefs about health, memory loss and family obligation; and, varying immigration patterns, the core components of the model—the care advocate, community outreach and education, and partner cross-training—remain the same. The goal of the project within each community is to determine the most effective strategies of service delivery to reflect the nuances of the target community.

Created for community-based providers and agencies that wish to replicate the Dementia Care Network service delivery model in their communities, a replication manual exists and is available through the website:

www.alz.org/californiasouthland/in_my_community_professionals.asp.

The 85 page manual includes: a general overview of the model, its structure and components, key considerations, phases of development, profiles of the model’s implementation in the Asian American, Latino and African American communities, and sample forms. An accompanying CD provides sample forms, which can be adapted to suit the needs of individual projects. The Alzheimer’s Association agrees to full disclosure of all pertinent details to enable any other service provider to replicate the Dementia Care Network and provide a contact person to offer technical assistance to other agencies.

In order for another agency to replicate this project, the largest expense would be the two staff positions: one with dementia specific knowledge and one care advocate for the targeted community. Additional funding for creating culturally and linguistically appropriate literature would be a benefit although there is a wide range of materials in a variety of languages that already exists. Providing respite funds to reimburse families seems to have attracted some families to the project initially; they later benefited from the support and education.
Caregiver Education Programs

How was the award money used?
The award money was used for the following program enhancements:

- Chinese booklets (45 pages) about Alzheimer’s disease were printed; these booklets are an educational tool to reach out to Chinese monolingual speaking families.
- Brochures about brain health were printed in four different Asian-Pacific Islander languages.
- Consultants were hired to assist the Association create a manual for other organizations interested in replicating the dementia care network model; tips sheets were developed and printed on replicating the model for the Asian-Pacific Islander community.
- An Alzheimer’s Association staff person presented the dementia care model at a national conference so that others could learn from the model’s success.

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Powerful Tools for Caregivers
Legacy Caregiver Services
Portland, Oregon

Powerful Tools for Caregivers is a highly effective educational program providing family caregivers with the skills and confidence to better care for themselves while caring for someone with a chronic illness.

Background & History
Powerful Tools for Caregivers (PTC), developed by Legacy Caregiver Services, is part of Legacy Health System, a Portland, Oregon, non-profit healthcare organization. The PTC program and all materials were developed over 3 years of pilot testing, refinement and evaluative research to assess the program’s effectiveness. Initiated through grant funding, the program has been offered for over 8 years.

Goals
PTC is a six-week education program that helps family caregivers of older adults to develop and practice self-care “tools” to thrive as individuals while managing caregiving responsibilities. In the six 2½ hour classes, caregivers develop a wealth of self-care tools to: reduce personal stress; change negative self-talk; communicate their needs to family members and healthcare and service providers; communicate more effectively in challenging situations; recognize the “messages in their
Caregiver Education Programs

emotions” and how to deal with difficult feelings; and make tough caregiving decisions—e.g., when a family member can no longer live alone, drive safely, or manage his or her finances.

Program Description
Classes are held at locations such as churches, and community centers and are taught by pairs of trained facilitators who use a standardized curriculum that employs a variety of teaching strategies including didactic presentations, group discussion, brainstorming, modeling, role-playing, and action plans.

All Class Leaders receive PTC training materials including the Class Leaders’ script, flipcharts/overhead transparencies, video, relaxation exercises. Caregivers also receive The Caregiver Helpbook, a supplemental guide written especially for the course. This book is available in English and Spanish. A 90-minute six-week series and an on-line version of the program have been developed.

PTC is based on the highly successful Chronic Disease Self-Management Program developed by Dr. Kate Lorig and her colleagues at Stanford University’s Patient Education Research Center. Powerful Tools for Caregivers is a national program sustained by extensive collaborations with community-based organizations. As of 2007, the program has reached more than 15,000 family caregivers in over 20 states.

PTC is exclusively focused on self-care of the family caregiver, not on the care receiver. PTC has a unique, proven ability to increase a caregiver’s self-efficacy, better manage emotions, increase self-care behaviors, and utilize community resources. The program incorporates weekly action plans, which serve to build confidence in being able to practice self-care behaviors. Initially developed for caregivers to older adults, PTC has been found to benefit all caregivers of adults with chronic illnesses and shows great promise to other populations, such as caregivers of children with disabilities.

Thus far, over 1000 Class Leaders in 23 states have been trained to deliver PTC in community-based settings.
Caregiver Education Programs

Class Leaders have taught PTC to more than 15,000 caregivers. Based on research evaluation, significant outcomes are documented at 6 and 12 months after classes. PTC has been shown to have a positive impact on caregiver health for a diverse group of caregivers including rural, ethnic minorities, adult children of aging parents, well-spouses, caregivers in different stages of caregiving, living situations, financial and educational backgrounds. Data from class participant evaluations indicates: Significant improvement in behaviors: increased exercise, use of relaxation techniques and health self-care; improved emotions, including reduced anger, guilt, and depression; increased self-efficacy; and increased use of community services. Since the program’s inception, over 50,000 copies of *The Caregiver Helpbook* have been distributed.

Initiated with funding from the Northwest Health Foundation, The Robert Wood Johnson Foundation, and the Good Samaritan Foundation; PTC has undergone extensive testing in rural and minority communities. Because the program utilizes a variety of different teaching techniques including small and large group discussion and making action plans, caregivers are able to individualize the program and adapt it to their culture. The program emphasizes the importance of class leader modeling and co-leaders are often from the community (e.g. rural, ethnically diverse, etc.) they serve. Pilot testing and continuing use of the curriculum have shown that the curriculum did not need cultural modification. PTC materials are available in both English and Spanish and parts of the curriculum have been translated in Korean, Vietnamese, Chinese and Portuguese. Currently PTC is working towards the expansion and any necessary modification of the program to serve Native American caregivers, employed caregivers, and grandparents raising grandchildren.

**Partners**

To sustain the program post grant, multiple collaborations and partnerships of varying levels of commitment have been developed with staff at organizations such as:

- Area Agencies on Aging
- AARP
- Cooperative Extension System
- Parish Nurses

**Challenges and Barriers**

One of the greatest challenges in working with the caregiving population is self-identification of caregivers. Wording of printed materials and more importantly, conducting outreach talks with groups of caregivers aids in cultivating awareness on behalf of family and friends that they are, in fact caregivers. A one time, 60-90 minute program excerpted from the curriculum on the topic of Managing Caregiver Stress (a topic that attracts
Caregiver Education Programs

many), has assisted with attracting caregivers to the full six-week series. When conducting the 3-year research and demonstration grant with The Robert Wood Johnson Foundation (RWJF), Northwest Health Foundation, and Good Samaritan Foundation, it took a great amount of time to hire and mentor multicultural outreach staff and to develop relationships for reaching underserved rural and ethnic minority communities. Establishing rapport with these targeted groups requires substantial time. The original proposal was for a four-year project with a six-month start up phase before conducting Class Leader Trainings and Caregiver Classes. The project was funded for three years not four, and training was begun too soon after the grant began, cutting into the crucial valuable start up phase. In hindsight, it would have been wise to have revised the objectives from the beginning of the project. The project also would have benefited from utilizing the RWJF network of other programs around the country with experience in working with underserved rural and ethnic minority groups to learn from their experiences and program evaluation (e.g. translation, culturally-appropriate outreach, volunteer recruitment and retention).

Another significant challenge was economic downturn that affected Oregon during the grant period (2000-2003). Severe budget cuts at the state level and reduced services affected the ability of many non-profit organizations to support the Powerful tools for Caregiving program and other programs that were not considered critical to core business. Although the Area Agencies on Aging (AAA) received federal Administration on Aging funds for family caregiver programs, it was difficult for many AAA’s to allocate these funds during a time when staff were being downsized and the need to focus on supporting core emergency services was the priority. Despite this challenge, the program was extraordinarily successful. In outreach efforts, we emphasized that Powerful Tools for Caregiving is a cost-effective, “packaged” program. Many AAA directors, although not all, saw the Powerful Tools program as a readily available resource that enabled family caregivers to take better care of themselves within the environment of limited public services. The project worked successfully with non-profit agencies and AAA’s by promoting the positive outcomes of the program as well as the ability to offer training without cost during the grant to gain support. To aid program sustainability, the project required a support letter from each agency sponsoring a Class leader. This letter of support was strongly weighted in the selection of a Class Leader to become trained and enabled the program to build strong partnership relationships with community organizations.
Caregiver Education Programs

Program Evaluation
PTC utilized extensive caregiver and self-efficacy literature review. It employs adult learning principles combined with the principles of self-efficacy pioneered by Dr. Kate Lorig's widely acclaimed chronic disease self-management model. Developed out of a series of 10 focus groups with diverse groups of caregivers, PTC was pilot-tested and refined in Oregon. Subsequently, comprehensive evaluations of outcomes have been completed among hundreds of PTC participants in separate studies conducted in Oregon (Boise, Congleton & Shannon, 2005) and Illinois (Kuhn, Fulton & Edelman, 2003). Positive outcomes for caregivers are consistently reported in pre-class, post-class, 6 and 12-month comparisons of diverse caregivers.

Lessons Learned
Collaboration with a multitude of human service organizations is vital in sustaining the program over time. Without the support of the Area Agencies on Aging, AARP, Cooperative Extension Service, Parish Nurses, Churches and numerous other human service agencies, the program would have closed its doors post grant, as too many excellent projects do.

A ready-made product will enhance wide dissemination of the program and the sale of this product will generate funds to sustain the program. The PTC program has scripted curriculum materials to disseminate as well as a book, The Caregiver Helpbook, to sell and recoup some of the costs of the program. The utilization of skillful outreach workers indigenous to their community and/or culture to promote the program is vital to the success in reaching out to rural and underserved ethnic minorities.

The Powerful Tools for Caregiving program content is culturally appropriate for the underserved rural and ethnic communities it served. This is due to the curriculum design, which provides the opportunity for class participants to individualize the program to their caregiving situation (e.g., brainstorming, paired/group discussions, making action plans to apply class curriculum to their personal situations). Training co-leaders from the communities/cultures served was also important to the program's success. The program was well received by diverse ethnic communities when translated into their native language. In working with diverse ethnic groups, it was interesting that cultural assumptions of what would work and not work for a community were challenged. Before offering a class, the process of discussing the need to modify the curriculum was important, as was the consensus to pilot test the program without modification. All were pleasantly surprised to find it extremely well received and judged culturally appropriate, once tried. Thus, the project would recommend that other programs conducting outreach to ethnic communities consider first testing their program.
without modification to determine if it is culturally appropriate or not and then make modifications based upon the feedback received from participants, rather, than to first use input from focus groups to make changes in the curriculum prior to pilot testing.

Outreach to multicultural communities requires a great deal of time. Long timelines need to be allowed in planning a project. Traditional methods (e.g. printed brochures) may not be successful if used without personal contacts to key organizations and individuals with those cultures with significant language, economic, and literacy barriers. Outreach strategies at all levels—upper management as well as grass roots—is important to reach out to underserved populations.

Translation involves much more than word for word translation and must include pilot testing and adequate time and resources for revisions as needed. It is important to have team members who are bicultural as well as bilingual for outreach, and to recognize that the intended target audience (e.g., Latinos) may have a great diversity of English and other language ability in speaking and reading due to where they were born, number of years in the U.S., education level, etc. This makes it difficult to develop one set of educational materials (or publicity) that will fit all needs. It is also important consider the need for translation of the many program support materials for a monolingual minority community.

Creative strategies for support are needed to sustain a program in underserved rural and ethnic minority communities. Because these groups are struggling economically and may be overburdened in trying to meet a multitude of basic needs for their community, substantial barriers impede community organizations from supporting a new program. This project provided a support fund to address transportation, respite and day care for class leaders and caregivers. This project was based on training and mentoring volunteer or agency-supported Class Leaders. While many class leaders had the support of their employer to co-lead classes and attend the four-day training, it was difficult to recruit interested persons from ethnic and rural communities. A stipend for those communities with severe economic challenges may be important to gain the commitment needed for the program’s success. The project has begun to look at offering a stipend to these leaders in partnership with Area Agencies on Aging.

When planning a project, it is important to factor in an attrition rate in estimating numbers. In this project we experienced a slightly lower than anticipated attendance in classes, especially in some of the most rural communities. Also, the number of class series conducted was...
Caregiver Education Programs

less than originally calculated because 1) a drop out rate for class leaders was not originally calculated, and 2) the project did not anticipate that leaders would experience delays in teaching caregiver classes (both with reasons including juggling caregiver responsibilities and job demands).

_It is important to balance the need to accomplish project objectives with flexibility to respond to unanticipated opportunities_. Had the project not maintained an open mind to opportunities along the way, it would not have reached out to the Korean, Chinese, Vietnamese, communities, nor cultivated numerous partnerships with such a diverse group of community agencies. Mid-project, with support from its funders, the project realized that it would not reach the numbers of caregivers served during the grant period. However, the commitment to the labor-intensive outreach required to reach the underserved was reaffirmed and over time has proven to be fruitful for the population served.

**Replication**

PTC is disseminated by offering affordable Class Leader and Master Trainer trainings to a variety of health and human service agencies. It is a train-the-trainer model scripted curriculum. All program materials are given to the leaders at these trainings. These agencies replicate and sustain the program through statewide networks thereby expanding the number of caregivers served. Class Leaders have been trained in 23 states. Currently, Alberta, AZ, CA, IA, IL, MT, NC, NY, OR, WA, and WI have Master Trainers in addition to class leaders. The goal of the program is to expand the program in all states with Master trainers in each to provide the capacity to replicate the program through their own networks.

**How will the award money be used?**

The program will be enhanced by the award money received from the National Family Caregiving Awards by training additional Class Leaders and Master Trainers to more widely disseminate the program.

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**References**

Caregiver Education Programs

JustCare: Caregiver Education Project
Bet Tzedek–The House of Justice
Los Angeles, California

As an innovative legal aid program, JustCare offers pioneering educational trainings and clinics to low-income caregivers, disabled adults and professionals throughout Los Angeles County promoting knowledge about advance planning and protecting seniors’ full and equal access to rights and justice.

Background & History
One of the nation’s premier poverty law centers, The House of Justice – Bet Tzedek Legal Services offers highly innovative, unique, and effective strategies to address the major problems confronting the more than two million low-income, disabled, and elderly Los Angelenos disenfranchised by poverty. Bet Tzedek’s pioneering approach of direct legal representation combined with outreach, education and training directly empowers thousands of vulnerable people with the knowledge and tools needed to protect their rights, ensure full and equal access to justice, and vital necessities like safe and affordable housing, fair wages, health care, and public benefits.

Goals
JustCare: Caregiver Education Project empowers low-income disabled adults and their caregivers with the legal training and tools they need to attain equal access to rights, benefits, services and justice; increases the capacity of service agencies to identify and address the legal needs of caregivers; improves the quality of care available to low-income disabled adults and their caregivers; and serves as a national model, sharing its exclusive expertise.

JustCare was designed specifically to address economic, language, cultural, ethnic and racial barriers within the caregiver community. Staff regularly conduct community legal education presentations in Spanish, English, Russian and Asian-Pacific Islander languages for health-care professionals, social workers and caregivers themselves. Clinics and workshops are specially tailored to the needs of diverse populations.

Program Description
Since 1992, Bet Tzedek’s innovative JustCare: Caregiver Education Project has pioneered groundbreaking community models in legal literacy, and today is the leader in helping over 4,000 low-income disabled adults and their caregivers equally access the justice system each year. Through its innovative integration of outreach, community education, and publications, JustCare effectively empowers a broad diversity of
low-income people with resources and information on how to avoid victimization, safeguard their rights, and address basic legal issues.

The majority of low-income disabled and elderly adults and their caregivers face complex legal problems in accessing and maintaining social services, housing, healthcare, physical safety, public and private benefits. Without proper legal guidance, minor problems can quickly escalate to a crisis point—and since most social service providers do not provide legal aid or advice, caregivers’ urgent legal needs go undetected and unaddressed and homelessness, institutionalization, bankruptcy, and poverty are too often the result. These problems are exacerbated by geographic, language, and cultural barriers that further marginalize low-income seniors and disabled adults, and prevent their knowledge of and access to vital services, benefits and civil rights.

JustCare has served nearly 60,000 caregivers with direct services, and reached an estimated 500,000 caregivers through its publications and materials. JustCare includes the following components:

- **JustCare Workshops**: Free, multi-lingual workshops educate, connect and empower 4,000 low-income caregivers each year to protect their rights. At community centers and stakeholder agencies throughout Los Angeles, staff provide plain language, easy-to-understand explanations of legal rights and protections.

- **JustCare Trainings**: These innovative trainings are for professionals and agencies who provide services to caregivers.

- **JustCare Publications**: Released in June 2007, *The Caregiver Companion* is the only resource of its kind in California. The manual addresses the most frequently encountered problems and issues surrounding the complex laws and regulations governing caregiving, and answers the most common questions of caregivers and their disabled family members.

- **JustCare Clinics**: Empowering caregivers with the tools they need to address basic legal issues on their own, topics include *Advanced Healthcare Directives and Planning for Long Term Care and Incapacity*. In 2006, Bet Tzedek presented more than 100 clinics to more than 750 caregivers and families throughout the County.

- **JustCare Outreach**: Bet Tzedek attorneys and paralegals visit nearly 100 community centers throughout isolated areas of Los Angeles City and County, ensuring that caregivers and their families have access to a wide array of educational programs.

**Caregiver Education Programs**

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**Lessons Learned**

Lesson #1: Go to where the clients are. Choose workshop sites that are easiest for clients to access.

Lesson #2: Connect (and re-connect) with as many partners as possible.
Caregiver Education Programs

- Cedars-Sinai Hospital System
- Alzheimer’s Association
- Public Guardian, and others.

These partners serve the same clients as JustCare, and were chosen because they complete an integrated network of service providers.

Outreach
Caregivers learn of JustCare either through its community workshops or its partners.

Challenges and Barriers
JustCare’s clients constantly struggle with access issues. JustCare staff has also had to adjust programming or create new programming to address newly-identified barriers or service gaps.

Program Evaluation
JustCare is evaluated regularly. The various funding sources all require evaluation on a quarterly or yearly basis. Evaluation methods include client surveys, focus groups, client data, and case review.

Replication
Any legal services organization with the desire to serve caregivers and a commitment to community outreach can begin this work. At its core, it requires the expertise of one attorney who can perform community workshops. With an $850,000 budget, four-staff project, the full scope of JustCare could be appropriately administered by a legal
Caregiver Education Programs

services organization in the $2-6 million range.

Bet Tzedek is committed to the full disclosure of its expertise, resources, and program design to enable full replication. JustCare encourages social service and government agencies to include a legal needs assessment component to their intake procedures, and educate their staff about recognizing legal issues.

How will the award money be used?
Bet Tzedek will use the $25,000 award to support its education and outreach efforts. Annually, the Family Caregiver Project team reaches nearly 3,000 caregivers and service professionals with expert training and guidance. In 2007, the Family Caregiver Project team promoted the new Caregiver Companion consumer guide, which uses plain language to describe the many benefits and rights that caregivers possess.

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Alzheimer’s Caregiver Series
Montana State University Extension
Bozeman, Montana

Developed by an interdisciplinary team in response to a community request, this highly successful educational program provides an effective approach in assisting rural caregivers cope with the multi-faceted aspects of Alzheimer’s disease.

Background & History
Montana is a rural state with approximately 944,632 residents. The State is the fourth largest in land mass in the nation with 6.2 persons per square mile; therefore, most of the state is considered frontier. The Alzheimer’s Caregiver Series was developed within the context of serving caregivers in a very rural state.

Montana State University (MSU) Extension is a statewide educational outreach network that applies research-based university resources to practical needs identified by the people of Montana in their home communities. In the MSU Extension unit of Family and Consumer Sciences, MSU has five specialists covering the areas of Family & Human Development, Family Finance, Housing and Environment, Food and Nutrition, and Nutrition Education.
Since 2002 the MSU Extension Service has been working with the Alzheimer’s Association Montana Chapter to increase the awareness and support for family caregivers through assistance with conferences and participation on the board of directors. Although conferences on the topic of Alzheimer’s disease are held annually, the location and time away from caregiving precludes most rural caregivers from attending. This need led to a request to hold a conference in a rural area of the state.

**Goals**
The goal of the MSU Extension Alzheimer’s Series is to provide research-based educational information for informal caregivers providing care to a friend or loved one with Alzheimer’s disease, specifically those in the rural areas of Montana. Success is measured by assessing what participants learned and what activities were implemented to assist them in their caregiving role. Overall success would be that caregivers are practicing better self-care.

**Program Description**
An estimated 16,843 people in Montana have been diagnosed with Alzheimer’s disease with more than 70% of Alzheimer’s patients living at home and being cared for by family members or friends (Alzheimer’s Association, 2005). Due to the rural nature of the state, Alzheimer’s patients and their families are often isolated with few resources and supports, creating greater challenges for caregiving. To assist informal caregivers in learning more about the disease of Alzheimer’s and to help them understand the importance of self care, the five-week *The Alzheimer’s Caregiving Series* was developed. The first series was offered in the fall of 2005 in northeast Montana. Since the inception of the series, 233 caregivers have been served.

Originally the State Extension Specialists planned to have a one-day conference in northeast Montana targeting family caregivers of individuals with Alzheimer’s. Feedback from community professionals/practitioners and constituents suggested that a better approach for the family caregivers would be for each specialist to spend a week in the area presenting his or her seminar in several communities. For example, the nutrition specialist presented her seminar on nutrition in six different communities over the course of the week. This allowed more caregivers to participate in the series without having to leave their community. The result was the development of a five-week educational series using diverse effective adult educational strategies in two and a half hour seminars focusing on: 1) an introduction to Alzheimer’s disease; 2) family interactions and caregiver stress; 3) nutrition; 4) financial planning and legal issues; and 5) Alzheimer’s proofing the
Caregiver Education Programs

home. Thus series was titled The Alzheimer’s Caregiving Series. The planning phase of the program took approximately six months. First, a commitment was obtained from the Extension Specialists and County Agents involved. Each Specialist then developed a two and a half hour class related to his/her specialty. The County Agents worked at the local level to find cosponsors for the program, develop a schedule, recruit participants, and facilitate other local logistics. One of the most difficult aspects was finding five consecutive weeks where the Specialists can go out to the various counties. This required planning several months ahead of time.

Program Partners

- Extension County Agencies
- Montana Chapter of the Alzheimer’s Association
- Montana Department of Public Health and Human Services, Senior and Long-term Care Division
- Local hospitals, senior centers, and long-term care facilities

These partners were selected because of their interest in providing caregiver education and because they had contacts with informal caregivers.

Outreach

The program reaches the caregivers in the local communities through the outreach of the program partners. Additionally, the County Extension Agents placed articles in the local newspapers, advertisements on the radio, and distributed posters about the series.

Challenges and Barriers

The greatest challenge is finding the time to offer the series in its entirety. This requires five consecutive weeks. Not only is it a challenge for the presenters but also for the participants to commit to the five weeks. Packaging the program so that it could be offered by one educator will assist overcoming this challenge. The other challenge is finding respite care for the Alzheimer’s patients. Staff has been fairly successful in overcoming that by working with the local hospitals and long-term care facilities.

Program Evaluation

The evaluation was based on the logic model. Data were gathered at three points of time. Short-term outcomes were measured through a pencil and paper evaluation given at the end of each seminar. A telephone interview six weeks after the end of the series with a random sample of 14% of the participants assessed medium-term outcomes. A telephone interview conducted four months after the end of the series with another random sample of 11% of participants assessed longer-term outcomes. Results from the short-term evaluation of the seminars revealed: 48% of participants either planned to or had already started exploring alternatives for handling the financial affairs of the Alzheimer’s patient; 61% planned to use the housing checklist for home modifications; 69% planned to find respite care for themselves at least
once in the next month; and 60% strongly agreed with the statement, “Based on the workshop, I better understand the food/nutritional needs of people with Alzheimer’s.”

Six weeks after the series ended, 81% of those interviewed stated they had shared information with at least one other person, thus increasing the number of people benefiting from the program. One person stated: “I am using the nutrition information and it (the program) has helped me to more or less recuperate from the stress of taking care of my mom because I was the sole caregiver.” Four months after the series ended, 89% had increased their self-confidence in caregiving. One hundred percent reported being better prepared for their caregiver role.

**Lessons Learned**
The greatest lesson learned from the program’s experience was how great the need is for information on caregiving. Few resources on Alzheimer’s were available in Montana’s rural areas. By offering the series, rural residents were able to network and meet others who were in the same situation. This allowed an opportunity for the participants to learn about local resources. Although the series targets the informal or unpaid caregiver, in some areas CNAs and other health professionals participate. Hospitals and long-term care facilities in rural areas often do not have the resources to send staff to training outside of the community.

**Replication**
MSU is currently packaging the series for easy replication and use. The package will include instructional guides, Power Point presentations, DVDs used in the seminars, fact sheets, and information on other resources. MSU plans to make the package affordable to encourage widespread use by those who work with informal caregivers. The “Alzheimer’s Series Planning Kit” will allow professionals who work with caregivers to offer the program.

**How will the award money be used?**
The award money will be used in three ways. It will help the project team complete the packaging of the series for sale and distribution. Some funds will be used to offer the program in other areas of Montana. Finally, the project team will use some funding to offer the Powerful Tools for Caregivers program in Montana, which is a natural extension of the Alzheimer’s Series for caregivers who would like more information (see page 46 for more information about Powerful Tools for Caregivers).

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Technology Programs

Supporting Caregivers through Technology
Family Caregiver Alliance
San Francisco, California

This organization has a long history of success and innovation, and has used and been effective with multiple types of technology to address the needs of family caregivers.

Background & History
Family Caregiver Alliance (FCA) is a not-for-profit organization that offers programs at national, state and local levels to support and sustain caregivers. Founded in 1977 by a small task force of families and community leaders in San Francisco, their commitment was to create support services for those struggling to provide long-term care for a loved one who did not “fit” into traditional health systems: adults with Alzheimer’s disease, stroke, Parkinson’s, traumatic brain injuries and other debilitating disorders. Despite diverse diagnoses, the founding families shared common challenges: isolation, lack of information, few community resources, and changes in family roles. Their efforts formed Family Caregiver Alliance; began a statewide network of Caregiver Resource Centers (CRCs); and launched a national movement to recognize the immense contribution of family caregivers to the long-term health care of the ill and older persons in the United States.

Today FCA, with a staff of 33, is a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy. As the Bay Area CRC, FCA each year directly helps about 3,000 family caregivers who live in the greater San Francisco Bay Area. As the Statewide Resource Consultant, FCA assists the California Department of Mental Health in overseeing and advancing the statewide system of CRCs. As the National Center on Caregiving (NCC), FCA collaborates to accelerate development of high-quality, cost effective programs and policies for caregivers in every state in the country. FCA’s website—caregiver.org—has over a million visitors annually and its consumer information is featured in numerous websites such as the Library of Medicine, Healthline and others. In addition, the NCC responds to over 2,000 requests for assistance from caregivers across the country annually.

Goals and Program Description
For over 20 years, FCA has used technology as a solution throughout
its programs, beginning with data collection and program reporting for the California Department of Mental Health and the California CRC system. Since 1990, FCA has concentrated on using technology to support family caregivers through education, services, research and advocacy, utilizing technology to further its core mission. There are programs that FCA has undertaken that can be lifted and used by most community organizations but there are other functions—like the website—that leverage FCA’s key core competencies of information and policy development that may be beyond the capacities of some organizations or not fit into the overall mission of service organizations. Under each section, information will be provided that covers practical considerations like budget and staff requirements and collaborative partnerships needed for a successful project.

Each use of technology responds to a problem defined by caregiver need or an enhanced communication strategy. FCA tracks trends in technology innovation and applications, always asking: “What’s useful at FCA? What is effective in disseminating policy and program data and in promoting grassroots advocacy efforts? How can we extend services to caregivers in a convenient way?” Technology solutions and experimentation are supported by FCA leadership and training has been done over the years to promote ease of use by staff. FCA has also formed partnerships with experts and researchers in technology to determine the most cost-effective means to meet the agency’s mission and serve its multiple audiences of researchers, policy makers, and families.

Most of FCA’s technology innovations have been grounded in research, whether it is analysis of client data from the eleven Caregiver Resource Centers, field research in the 50 states, or online chronic disease self-management research (the basis for Link2Care). FCA continues to seek cost-effective methods to determine outcomes across its technology programs. Other programs, such as the Northern California Rural Caregiver Collaborative, have independent evaluators who bring their expertise in telehealth and telemedicine.

Currently all of FCA’s technology projects are conducted in English with the exception of the availability of consumer information in multiple languages on the FCA website. However, many of the education projects have targeted rural and frontier communities in California. A pilot test was conducted to test a Spanish language workshop by conference call in spring 2007 in collaboration with the Alzheimer Research Centers in California.
Technology Programs

Projects, Services, and Replication Strategies

Education Projects
FCA developed and coordinated two Statewide Videoconference efforts, first in 1990 using satellite technology for sessions on legal planning and behavior management to 60 sites and in 2002, workshops on dementia care, Parkinson’s disease and Huntington’s disease held at 25 libraries, community colleges, schools and other community locations using Internet-based technologies. In 2005, FCA turned to Telephone Conference Call technology to deliver a three-part workshop series (long distance caregiving, behavior management, sibling negotiations) targeting rural and isolated caregivers and in which close to half of all participants were between 60 and 80. The teleconferences build on simple, ubiquitous telephone technologies that are free to the end user (a toll-free number), do not require transportation or substitute care of the care recipient, and can be scheduled during the day or evening hours. Best conducted in partnership with community organizations, which can market and encourage participation by their clients, teleconferences offer a convenient, low-cost opportunity to reach those who may have never attended a community workshop. About 50% of the CRC teleconference participants had never attended a caregiver education program in the community.

Generally across the country, investment in community videoconference technology infrastructure can be found in libraries, rural hospitals, health clinics, schools, distance learning centers, and county offices. These resources may be underutilized, depending on the community. Some, like telemedicine technologies, may have very busy periods of use during office hours but lay dormant after hours while libraries may not have trained staff to operate equipment after initial grants have expired. Despite some of these shortcomings, there exists in many parts of the country the infrastructure to conduct these programs with a likely expansion of telemedicine capabilities at the rural hospital and health clinic levels. Videoconference technology has the advantage of scalability to cover a local network, or regional or statewide capacity. It also offers interactivity depending on the number of sites involved. Videoconferences work best for topics needing a demonstration like the body mechanics of lifting a care recipient. Costs vary widely for use of these facilities although some sites may not have a use charge for community programs.

Conference call technology has the advantages of using an ubiquitous technology—the telephone—to deliver short (60 to 90 minutes) workshops. While this project usually requires an outside conference call...

All community organizations should have a presence on the Internet. It is the way a majority of consumers will look for information in the community in the near future and it offers wide marketing opportunities.
service that can handle hundreds of callers, the price of this technology has decreased over time and the cost per minute has dropped to $0.07/minute per caller recently. Using skilled staff in collaboration with experts in health, mental health, care management or legal areas, a focused hour of education can be provided for less than $10/per person (including marketing costs, telephone charges and registration costs).

Both of these programs need dedicated staff (1-2 depending on the size of the program) with backgrounds in education and aging issues working part time over a number of months to: identify the videoconference sites and the broadcast site; determine any cost of use for videoconference sites (some may be free, others need a fee for staff to be present during the program); set up agreements with a conference call vendor; possibly organize volunteers to be “greeters” and facilitators at the local videoconference sites; organize a planning committee; develop and disseminate marketing material; organize and train speakers; collect workshop handouts; conduct introductions to the programs, and evaluate the results. Both types of programs are great partnership or coalition building opportunities. In fact, they will not succeed unless there is a wide variety of partners who can contribute expertise to planning and conducting the programs, resources for marketing to their clients and the general community and potentially identifying locations and volunteers to assist with the program. On statewide programs, FCA has had between 11 and 30 partners involved on some level of the project. In addition, both programs offer the possibility of targeting caregivers who need education in other languages and who may be spread out over a wide area that make smaller, in-person programs more expensive.

Recognizing the growing importance of the Internet and changing caregiving demographics towards more adult children, FCA launched its Website (www.caregiver.org) in 1995 with an emphasis on practical content for caregivers. Receiving over a million visits annually and averaging over 2,000 e-mail requests for assistance from caregivers nationally, it has won numerous awards for content and design.

However, there is a difference between having a web presence and operating a data-rich, interactive website. Unless an organization has as its core mission creating consumer information for wide dissemination or has significant capital to create original content or pursue licensing agreements to place content from other organizations or authors on their website, this is a very costly venture in both start up and maintenance. All service agencies should have a site that clearly states

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The key to technology adaptation within FCA lay not so much in application of a particular program, but in an organizational culture that promotes technology as a possible solution to the challenges caregivers face and dissemination of information to various audiences.
their mission, services, eligibility, hours of service, fees, location, contact information (including email) and other information that could provide a full description of the organization. If staff are available, the community agency should update their site with local program information (new projects, educational events, etc.) and consider providing a venue for consumers to start their application for services online. Costs for a simple web presence range from a low of $2,000 to tens of thousands of dollars per year, depending on the scope and staff involved. At FCA, one of the core competencies is creating high quality consumer information, policy and research reports, and state databases that may be repurposed to suit a wide variety of audiences. The entire staff and a number of outside technology consultants are involved with the agency website, related technology initiatives, and information dissemination.

Service Delivery to Caregivers

In 1999 with funding from The California Endowment and in collaboration with the University of Wisconsin, Madison, FCA launched Link2Care (L2C), a web-based information and support service (www.link2care.net) for high-risk caregivers of adults with dementia. In addition to information about medical conditions, behavior management and other practical information, L2C provides caregivers with a wide variety of interactive programs, including Ask the Expert (for advice on medical and legal caregiving issues), Journaling (a virtual spiral-bound notebook with tips and exercises), inviting the caregiver to write confidential thoughts, then add to them or delete them as desired; and an online Discussion Group to share ideas, get peer support and escape feelings of isolation so common when caring for someone with a dementing illness.

Initially a five-CRC demonstration, L2C today is part of the CRC’s set of services and the only known statewide Internet-based service integrated within a traditional community-based caregiver support system. Currently over 1,800 caregivers participate actively in L2C, exchanging 10 to 30 messages daily through the Discussion Group and weaving technology-based solutions into their emotional support. For example, a caregiver seeking help to keep her parent from wandering away got tips within minutes on alarm systems—with links to vendors and installation instructions. In a 2004 satisfaction survey, 92 percent of the 208 L2C users surveyed said they were “satisfied” or “very satisfied” with service quality. Working in collaboration with the Alzheimer’s Research Centers in California, their clients will be able to enroll directly into Link2Care after clinical assessment. In 1997, FCA launched one of the first Online Support Groups for caregivers

“I am very grateful for all the help and support I have received from L2C. For someone who was as computer-illiterate as I was when I first logged on, it was easy to understand and access the different sites.”
with approximately 800 caregivers currently participating in a very robust (20 – 30 messages per day) caregiver discussion group using a listserv format.

Link2Care or similar type online support and education programs are recommended for consideration for large state or national organizations due to the initial investment and ongoing maintenance requirements. If organizations are considering a move into online services, it is strongly suggested that thought be given to licensing and modifying existing technologies. Another significant investment, aside from the site technology infrastructure is the initial cost of content development and ongoing maintenance. Again, this is an example of how FCA has leveraged its core competency of consumer information development into a different format for a targeted audience of CRC caregivers within California. Current staff for maintenance of the Link2Care site include the equivalent of one full-time staff person as well as technology consultants to refresh content, troubleshoot problems, create new programs and marketing materials and maintain contact with the CRCs for Link2Care questions and updates. The original grant from the California Endowment was for $333,000 and an estimated $150,000 has been spent in various platform and software updates during its operation. These figures do not include a valuation of content assets within Link2Care. For online support groups, the cost is fairly minimal—typically around $2,000 - $3,000 per group including monitoring—but marketing can be expensive. It has been our experience that unless you have a critical mass of around 300-400 participants using a listserv format, the group can be sporadically active at best. Bulletin board formats are very inexpensive but again, unless a critical mass uses your website, a call for help from a caregiver can sadly go unanswered for a long time.

FCA tracks service trends, caregiver characteristics, client satisfaction and reports on progress of the CRC system in California for the California Department of Mental Health. The data provides a rich context for determining new directions for service interventions and technology applications. In a current effort, FCA is conducting a project (the Northern California Rural Caregiver Collaborative) targeted to rural caregivers in partnership with a network of rural health clinics and hospitals to evaluate consumer preference and effectiveness of three modes of delivery for consumer education: videoconferences, teleconferences, and in-person programs. The evaluators are from the Kansas University Medical Center’s telehealth/telemedicine programs. FCA encourages additional research into consumer preferences and the

“I can’t tell you how much I appreciate being able to ask questions and receive your helpful and supportive answers. And, it is so useful to use the Internet, because I can ask the question and get the answer when it is troubling me and not have to wait for several weeks until I can see someone.”
Technology Programs

effectiveness of using technology to extend service capacity of organizations. However, from our experience, two critical conditions must be in place for a research project to be successful. First, there has to be an investment of training and support for staff in using technologies in service delivery; and second, there has to be an existing relationship with the communities targeted by the research.

Advocacy

State and federal policy makers, wanting ideas to improve policies for caregivers, inspired two other innovative uses of technology for advocacy. Since 2001, the bi-weekly Caregiving Policy Digest, sent by e-mail, has provided timely and relevant information such as new state and federal legislation related to caregiving concerns, state policy issues, national news, innovative programs, cutting edge research, conference opportunities, and media coverage on caregiver issues to over 3,000 subscribers. A recent example of how specialized information has worked in advocacy is how Washington State is now considering introducing legislation to include caregiver assessment within their Medicaid program. This is modeled after the state of Idaho’s legislation that was featured in Caregiving Policy Digest. The Caregiving Across the States Online Resource, based on FCA’s national field and survey research, became an interactive component of FCA’s website in 2005.

It has information for each state and the District of Columbia on programs funded through the National Family Caregiver Support Program, Aged/Disabled Medicaid waivers, and state-funded programs that either have a caregiver-specific focus, or include a family caregiving component in their service package. FCA, learning that caregivers were also using the Caregiver Across the States database to research available services, will leverage the 50-state data base with expanded consumer information set to launch in early 2008 on its website under funding from The Langeloth Foundation.

The power of using the Internet for advocacy purposes has been widely acknowledged as a viable and cost effective method for getting out key messages. FCA was neither the first nor the only organization providing policy information via email but the agency did focus its research and message to clear targets. In the Caregiving Across the States Online Resource, it came as a surprise that caregivers were using this section of the site as a way to understand benefits in an “at a glance” fashion since its original intent was to inform policy makers. Again, the agency used existing data as the core of building out a more consumer-friendly component of a resource data base of state level services for families. In these two programs, it is not the cost of technology that is the major consideration but rather
the skill of the staff and the ongoing maintenance of effort that ensures the integrity of the information in the policy digest and database.

**How was the award money used?**

The Family Caregiver Alliance used the award funds to make improvements to the consumer information on their website caregiver.org and to support staff who answer e-mail and telephone calls for assistance. The Family Caregiver Alliance answers over 1,500 inquiries from families nationally who respond to articles or programs featuring Family Caregiver Alliance or by finding their website on the Internet. Many of these families are looking for practical advice on locating services and financial supports in their own communities.

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**Technology Programs**

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**Long-Term Care Choices for Seniors, Families, and Caregivers**

**MinnesotA Help Network**

**Rochester, Minnesota**

**www.MinnesotaHelp.info**

“Connecting People of All Ages to Community Help”

**Background & History**

The Southeastern Minnesota Area Agency on Aging (SEMAAA) was State designated in 1981 to develop and fund programs in SE MN for seniors and family caregivers. SEMAAA is a 501c(3) private non-profit that administers Federal Title III, State, and foundation funds. The agency is a freestanding, single purpose organization with a Board of Directors consisting of 15 members who represent 11 counties.

SEMAAA’s mission is “Helping older adults and their families’ age successfully with dignity and informed choices.” The mission is accomplished through leadership, developing comprehensive planning, and forming supportive and productive collaborations within the aging network. SEMAAA administers approximately $2.2 million in funds annually and has a staff of 10 and a volunteer staff of 67. Services funded include senior dining, home delivered meals, legal, transportation, caregiver services, senior advocacy, peer counseling, and chore.

SEMAAA operates one of the seven call centers of the statewide Senior LinkAge Line®, a coordinated single
Technology Programs

access information and assistance service that provides in-depth assessment, one-on-one counseling, home visits, and forms completion. SEMAAA is a host of the Minnesota State Health Insurance Program that provides Medicare, Part D and private insurance counseling and resolution of claims.

In May 2006 SEMAAA added the Long-Term Care Choices decision tool to its array of services for seniors and caregivers. The modalities that were selected for the tool were identified by tracking the types of calls received by the Senior LinkAge Line® and the Hennepin County Human Services and Public Health aging and disability intake line for a three month period. Overwhelmingly, people called about housing needs, health insurance, daily living needs, such as meals, chore services, and transportation. Subject matter experts who are social workers, public health nurses, and policy planners developed the assessment questions. A second and third set of subject matter experts reviewed the questions for accuracy and made adjustments as necessary. The Alliance of Information and Referral Systems/InfoLine Taxonomy of Human Services was used to catalogue and classify the community service resource listings, which were tagged to the assessment questions. A survey was developed and located on the Long-term Care Choices tool to record user’s feedback.

Goals
Long-term Care Choices is a web-based decision tool for seniors, families, caregivers and professionals that can be used to identify needs, locate community services, and create a plan of care. People using Long-term Care Choices can learn about the various housing and care options that are available in Minnesota and receive a personal plan based on their needs identified through each section.

Program Description
Long-term Care Choices, www.longtermcarechoices.minnesotahelp.info, is comprised of eight assessments:

- Build Your Community Plan
- Daily Living Needs
- Health Insurance
- Housing and Modifications
- Safety and Security
- Planning Ahead
- Caregiving
- Memory Loss

The site also consists of a section outlining housing options, a page to help people to relocate from a nursing home, and a guide called Next Steps for families who want to begin talking about long-term care needs. People who use Long-term Care Choices can complete eight steps:

- Step 1: basic questions, such as gender and geographic location, that allow the site to customize
Technology Programs

the information based on the person filling out the tool and who the results are intended.

- Step 2: these questions result in a set of recommendations for long-term care that are displayed further along in the tool.
- Step 3: a questionnaire related to daily living needs and addresses Activities of Daily Living and Instrumental Activities of Daily Living.
- Step 4: questions about memory loss.
- Step 5: questions about health insurance.
- Step 6: questions about housing needs.
- Step 7: questions related to safety and security issues.
- Step 8: questions that facilitate people to think about planning ahead.

Users can answer some or all of the questions for Steps 3–8. A completed assessment will generate a set of local service providers and add the services to a plan that is forming behind the scenes. A **Skip** button is available for people to bypass an area that isn’t relevant to their needs. When the person has completed the questions and selected services to meet their needs, the survey can be printed or saved. Information is stored on a secure server that can be accessed only with a valid login and password. Multiple plans can be developed for the same person to track conditions over time or a single plan can be modified as needs change.

The tool is used while assisting callers to the Senior LinkAge Line® (which served over 120,000 callers in 2006) who were of all ages, races and ethnicity, as well as persons with disabilities. AAAs demonstrated the tool at public outreach events, and trained the service network and health insurance counseling volunteers to use the tool.

No other tool exists like this Long-Term Care decision. It can be individualized by caregiver and users can complete the sections that suit their particular situation. It is a simple tool that the user can save and update later as situations change. The tool empowers caregivers to have more control in developing the care receiver’s care plan on a continuing basis. The options for appropriate local services are updated each time the information changes and it allows updating with independent follow-up.

**Partners**

- Area Agencies on Aging
- Minnesota Board on Aging
- Minnesota Human Services—Aging and Adult Services and Disability Services Division
- Hennepin County Human Services and Public Health Aging and Disability Services
Technology Programs

- Metropolitan Center for Independent Living
- Center on Aging at the University of Minnesota.

The collaborative functioned for the purpose of planning, development, and testing phases of Long-term Care Choices decision tool.

Program Evaluation

All callers to the Senior LinkAge Line® are tracked through a statewide database. This data along with the web-site data provides information on the level of use of the tool and who is using the tool. Evaluation of the satisfaction with the tool will come later as further development occurs. Currently, users report satisfaction with ease of use and how comprehensive the web site is. Web metrics have been tracked since August 2006. Since that time over 5 million hits and 4,000 individual users have been reported on the site.

Lessons Learned

First, any state that attempts to develop a web-based Long-Term Care Choices self-assessment tool must first have a statewide Information and Assistance data base from which to draw the resource information that the tool needs to access in order to give guidance to caregivers.

Secondly, developers need a broad based collaboration of stakeholders involved in the development of the tool (or you could purchase the Minnesota version). Stakeholders from many disciplines, including technology specialists, must be involved to provide input, develop support, and joint financial investment in putting the tool up on the Internet. (this cost about a $500,000 for Minnesota).

Third, joint promotion with partners is required to get the word out about the tool and website. It was helpful for a tool like the caregiver self-assessment to be a part of a larger resource, such as the MinnesotaHelp.info, website that holds a wide range of information for seniors and their families.

Lastly, program staff needs to take the tool on the road to introduce it to county caseworkers, public health nurses, senior centers, and other service providers who will use it themselves or refer seniors and their caregivers to the site.

Replication

The SE MN Area Agency on Aging will provide full disclosure of all necessary details to enable replication of Long-term Care Choices. Technical assistance for replication by other states can be obtained from the State of MN and the University of MN.

The decision tool model has been adapted for other populations. A decision tool for youth transitioning
from high school to adulthood is in the final phase of testing and a planning tool for people with disabilities is in the development phase.

**How will the award money be used?**
The MinnesotaHelp Network plans to use the award money to begin reaching out to working caregivers through demonstrations in workplaces, development of promotional materials, and outreach to labor and workforce development organizations. The award will also support some of the maintenance and updating costs for the web-based tool.

**For more information**
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web: www.longtermcarechoicesminnesotahelp.info
### National Alliance for Caregiving Member Organizations

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<tr>
<th>AARP</th>
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<tr>
<td>ALS Association</td>
<td>National Association of Chain Drug Stores Foundation</td>
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<td>Alzheimer’s Association</td>
<td>National Association of Professional Geriatric Care Managers</td>
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<td>Alzheimer’s Foundation of America</td>
<td>National Association of Social Workers</td>
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<td>American Occupational Therapy Association</td>
<td>National Center on Caregiving/</td>
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<td>American Psychological Association</td>
<td>Family Caregiving Alliance</td>
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<td>American Red Cross</td>
<td>National Council on Aging</td>
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<td>American Society on Aging</td>
<td>National Hospice and Palliative Care Organization</td>
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<td>Caregivers of NJ/Epilepsy Foundation of NJ</td>
<td>National MS Society</td>
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<td>Center for the Advancement of Health</td>
<td>NavGate Technologies</td>
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<td>Easter Seals</td>
<td>Parkinson’s Disease Foundation</td>
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<td>Evercare</td>
<td>Pfizer Inc.</td>
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<td>Foundation for Health in Aging</td>
<td>State Farm</td>
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<td>Hamacher Resource Group, LLC</td>
<td>Sunrise Assisted Living</td>
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<td>Healthcare Leadership Council</td>
<td>U.S. Chamber of Commerce</td>
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<td>Home Instead Senior Care</td>
<td>U.S. Department of Veterans Affairs (DVA)</td>
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<td>Johnson &amp; Johnson</td>
<td>Verizon</td>
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<td>Kimberly Clark Corporation</td>
<td>Well Spouse Association</td>
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<td>LifeCare, Inc.</td>
<td>Women’s Institute for a Secure Retirement</td>
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<td>Lupus Foundation of America, Inc.</td>
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Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations that focuses on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

MetLife Foundation

MetLife Foundation was established in 1976 by MetLife to carry on its long-standing tradition of corporate contributions and community involvement. The Foundation has been involved in a variety of aging-related initiatives addressing issues of caregiving, intergenerational activities, mental fitness, health and wellness programs and civic involvement. More information about the Foundation is available at www.metlife.org.