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NATIONAL FAMILY CAREGIVING
AWARDS REPLICATION GUIDE

*The National Alliance for Caregiving
& MetLife Foundation*

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Acknowledgements and Background

Acknowledgments

The National Alliance for Caregiving is grateful to MetLife Foundation for its generous support of the National Family Caregiving Awards from 2006 to 2010. MetLife Foundation's commitment to family caregivers 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 to 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, technology, caring for adult children with developmental disabilities, 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 replication guide provides detailed information about the many programs that received National Family Caregiving Awards from 2006 to 2010. 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 National Alliance for Caregiving is appreciative of the awardees' time in writing summaries of their exemplary programs and their willingness to share replication ideas with other organizations and agencies that might be interested in implementing similar 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.

The grid on pages X-X is a summary of key characteristics of the caregiving programs in this guide and assists the reader to identify programs that have the most relevance for their caregiver populations and needs. The program descriptions to follow were written by staff from the award winning programs and include information on the programs' background and goals, partnerships, staffing, outreach, challenges and barriers, evaluation, and lessons learned, and information on program replication.

Replication Strategies

The following section presents a summary and analysis of the most important lessons learned and replication strategies from the MetLife Foundation/National Alliance for Caregiving National Family Caregiving Award winners. 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 all the programs follow this section.

Increasing Communication Among the Staff

Implementation of caregiver programs requires strong communication among the staff, volunteers and the caregivers. An effective program establishes delivery methods that allow everyone to work together and assist in many aspects such as grant writing, fiscal management, oversight for the course and volunteer management.

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 over emphasized. 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 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 startup costs, but also for sustaining the program over time. Sustainability planning must be discussed with program partners from the beginning of program planning.

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

Lessons Learned and Replication Strategies

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 program planning. 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 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. 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 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 consider the need for translation of 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 and education 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 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?

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 that is thoroughly trained.

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

Lessons Learned and Replication Strategies

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 a 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 over the past several years. Both videoconferences and conference calls are great partnership or coalition building opportunities. They will not succeed unless a wide variety of partners 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, including long distance caregivers to look for information in the community 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 a full description of the organization.

Discussion Groups and Social Networking

On-line discussion groups and social networking 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 serves, blogs, social networking sites such as Facebook may be used to facilitate the caregiver discussion groups.

PROGRAM CHARACTERISTICS

Page #	Education Focus	Support Focus	Serves Caregivers of Persons with AD	Technology Focus	Serves Caregivers of Adult Children with DD	Serves Diverse Population Groups	University or College Affiliated	Employer-Based Program	Volunteer-Based Program
2010 AWARD WINNERS									
12	✓	✓	✓			✓			✓
14	✓	✓	✓				✓		
16	✓	✓	✓			✓			✓
18	✓	✓	✓	✓					
20	✓	✓	✓				✓		✓
22	✓	✓	✓	✓		✓	✓		
25	✓	✓				✓	✓		
27	✓	✓			✓				
31	✓	✓			✓	✓			

Program Grids

PROGRAM CHARACTERISTICS										
	Page #	Education Focus	Support Focus	Serves Caregivers of Persons with AD	Technology Focus	Serves Caregivers of Adult Children with DD	Serves Diverse Population Groups	University or College Affiliated	Employer-Based Program	Volunteer-Based Program
2009 AWARD WINNERS										
<i>SAGE Caregiver Program</i> SAGE-Services and Advocacy for GLBT Elders New York, NY	34	✓	✓	✓			✓			
<i>Caring for Caregivers</i> Pro Bono Counseling Project Baltimore, MD	37	✓	✓	✓			✓			✓
<i>Caregivers Community Network</i> James Madison University Harrisonburg, VA	38		✓	✓			✓	✓		✓
<i>DARTS Workplace Eldercare Seminars</i> DARTS Minneapolis, MN	40	✓		✓	✓				✓	
<i>Dementia Skills Training for the Home Caregiver</i> The Copper Ridge Institute Baltimore, MD	43	✓		✓	✓			✓		
<i>Native Caring: A Conference to Learn, Connect and Share</i> Community Action Program of East Central Oregon Pendleton, OR	46	✓		✓			✓			✓
<i>Future Care Planning Services</i> Lifespan, Al Sigi Center and the Arc of Monroe County Rochester, NY	49	✓	✓			✓				

PROGRAM CHARACTERISTICS

Page #	Education Focus	Support Focus	Serves Caregivers of Persons with AD	Technology Focus	Serves Caregivers of Adult Children with DD	Serves Diverse Population Groups	University or College Affiliated	Employer-Based Program	Volunteer-Based Program
2008 AWARD WINNERS									
53	✓	✓	✓			✓			✓
56		✓	✓			✓	✓		
58		✓	✓			✓			
59	✓					✓	✓		
61	✓	✓		✓		✓			
63	✓	✓	✓			✓			

Program Grids

PROGRAM CHARACTERISTICS

	Page #	Education Focus	Support Focus	Serves Caregivers of Persons with AD	Technology Focus	Serves Caregivers of Adult Children with DD	Serves Diverse Population Groups	University or College Affiliated	Employer-Based Program	Volunteer-Based Program
2007 AWARD WINNERS										
<i>A Space of Beauty Journaling Program</i> Southern Caregiver Resource Center San Diego, CA	65	✓	✓	✓			✓			✓
<i>Home Educator Program</i> Alzheimer's Family Services of Greater Beaufort Beaufort, SC	69	✓	✓	✓						
<i>Powerful Tools for Caregivers</i> Portland, OR	71	✓	✓	✓			✓			
<i>Family Caregiver Project</i> Bet Tzedek Los Angeles, CA	75	✓	✓	✓			✓			
<i>Alzheimer's Caregiver Series</i> Montana State University Bozeman, MT	78	✓		✓				✓		
<i>LTC Choices for Seniors, Caregivers & Families</i> SE Minnesota Area Agency on Aging Rochester, MN	81	✓		✓	✓					

Page #	Education Focus	Support Focus	Serves Caregivers of Persons with AD	Technology Focus	Serves Caregivers of Adult Children with DD	Serves Diverse Population Groups	University or College Affiliated	Employer-Based Program	Volunteer-Based Program
2006 AWARD WINNERS									
84	✓	✓	✓			✓			
<i>Eldercare Partners Caregiver Services Eldercare Partners West St. Paul, MN</i>									
86	✓	✓	✓						
<i>Family Support Services Mount Empire Older Citizens, Inc. Big Stone Gap, VA</i>									
92	✓	✓	✓			✓	✓		
<i>Strengthening the Delivery of Family Caregiver Education through Partnerships Bethany Home, Inc. Waupaca, WI</i>									
94	✓	✓							
<i>Caregiver Manual Stroke of Hope North Palm Beach, FL</i>									
95	✓	✓	✓						
<i>Asian American Dementia Care Network Alzheimer's Association of Los Angeles, Riverside and San Bernardino Counties Los Angeles, CA</i>									
98	✓	✓	✓	✓		✓			
<i>Supporting Family Caregivers through Technology Family Caregiver Alliance San Francisco, CA</i>									

National Family Caregiving Awards

Care Team® Program

Interfaith CarePartners®
Houston, Texas



The family-centered Care Team® program of congregation-based trained and supervised volunteers provides respite to caregivers and multi-faceted robust relationships with cognitively or physically impaired persons, either in a family's home or through 3.5 hour activity programs at partner congregations.

Background & History

The Care Team concept and model of congregation-based volunteer caregiving began developing in 1985. No advance planning was needed because it was a response to Dr. Earl Shelp's research assistant's diagnosis of AIDS. He and Dr. Ron Sunderland invited a few others to share in the support of the research assistant. As they related to persons with AIDS and were moved by the intensity of their needs and absence of the faith communities, they began to educate clergy about the opportunity for a compassionate, non-judgmental ministry with this population. As clergy responded affirmatively, members of their congregations were recruited and organized into an AIDS Care Team® that was matched with persons with AIDS. They provided many forms of support and assistance until their deaths or other reason to end support. The concept and model was a work in progress during its early years and continues to be so. The program consists of students of caregiving, always learning and enriching the practices as the primary recipients of volunteer care have evolved to mainly frail older adults aging in place, including a significant population with dementia, and respite services for the caregivers of impaired persons.

Program Goals

The primary goal of *Care Team® Program* is to utilize the infrastructure of congregations to provide high quality and person-centered informal care to persons

who need support with socialization, activities of daily living (ADLs), and instrumental activities of daily living (IADLs), as well as respite for caregivers. This is achieved by recruiting, organizing, educating and training, and supervising volunteers who are matched with people to serve. The program measures progress with quantitative measures of activities and qualitative measures of impact.

Program Description

The program consists of about 2,000 congregation-based volunteer caregivers organized into teams. The volunteers serve over 1,800 total impaired persons and their caregivers annually providing about 130,000 hours of service in the program. About 40% of persons served are affected by dementia, about 55% physically impaired by chronic disease or age, and about 5% are impaired children or persons with HIV/AIDS. All persons served reside in the community, rather than institutional settings. Teams respond to the particular needs of each person that are appropriate for lay people to address. The relationship and support plan for persons served are evaluated monthly and revised as needed under supervision of the professional staff at Interfaith CarePartners. Particular forms of support may be transportation, companionship, socialization, and practical assistance in the home, assistance with ADL and IADL, and respite for caregivers, among other forms of support. Complementary services for caregivers are professionally led support groups and multiple educational and skill-building conferences for caregivers.

Timeline

The program is constantly engaged in planning and adaptation in the pursuit of excellence. The program evolves as new opportunities for service are identified and resources are available to support those activities.

Financial Issues

The organizing activities were all voluntary. Funding became an issue only after the caregiving program reached a size that there was not enough time to lead it through volunteers alone. The program was organized in a corporate structure in 1988. Its financial support has come from individual, corporate, congregational, foundation, special event, and government funding until 2008 when government funding was surrendered

because compliance requirements changed in a manner that would have compromised relationships with volunteers and partner congregations.

Staffing

Program design and content is managed by the president of the organization but ideas come from many sources. Each team of volunteers is supervised by a professional staff member who meets with the team monthly to review their activities, planning, team building, and continuing education. Staff is in contact with persons served, as well, in order to provide direct assistance and to support the teams in a more informed manner. There was no staff at the outset, only two professors who created the concept, initial practices, and coordinated activities. Presently, seven staff relate to about 2,000 volunteers in 115 teams. Staff is primarily master's level social workers or counselors, or experienced leaders of lay ministries in congregations.

Partners

Jewish and Christian congregations are the partner organizations. The efficiency and cost effectiveness of the programs build on the infrastructure and human resources of congregations. Congregations have joined and left the program over the years, but they remain the primary partners for service delivery.

Outreach

Families are identified from within the membership of partner congregations, referred by community service providers, or through self-referral.

Diversity

Teams generally serve people in their neighborhoods which mean that they serve people similar to themselves. Basic principles of the program are respect for personhood and a non-judgmental perspective. People volunteer knowing the characteristics of people served. Differences among people have not been an issue, perhaps because of the matching that occurs due primarily to location.

Challenges & Barriers

The first challenge was to address the stigma and fear of HIV. That challenge was met by education and reminding people of faith of a duty to care for

people with needs regardless of other considerations. Volunteers were similarly hesitant to embrace persons with dementia, not because of stigma, but because of a lack of knowledge and confidence. These matters were addressed through education and training. Parents of impaired children have been reluctant to entrust their child to volunteers. The program staff has accepted that some will and some won't, no matter how intense their distress or the efforts to gain their confidence. In short, program staff does the best it can and lives with the outcomes. Finance is a constraining limit, at times, but congregational readiness to participate in the program is an even greater hurdle. Persistence with recruitment and waiting for the 'teachable' moment are how the program staff responds.

Program Evaluation

An independent evaluation was concluded in March 2010 that focused on volunteers and clients, as well as program design and conformity. The evaluation produced several findings and concluded "The Care Team program is an effective tool in supporting impaired and frail elders in the community. In addition, the program provides a volunteer experience that enables participants to be effective and enjoy their work."

Lessons Learned

Lessons are always being learned. Relationships turn on the people engaged and the contexts and circumstances being addressed. The accumulated wisdom, experience, structure, and practices have been distilled in an internal publication available to all interested parties. It contains an instructional manual for organizing and conducting a caregiving team, a toolkit for use by teams to provide information and guidance during its life and work, and 30+ continuing education modules.

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National Family Caregiving Awards

New York University (NYU) Caregiver Intervention Center of Excellence on Brain Aging

New York University
Langone Medical Center
New York, New York



The NYU Caregiver Intervention (NYUCI) was designed to improve the well-being of caregivers of persons with Alzheimer's disease by mobilizing the support of naturally existing family networks, improving caregiving skills, and providing the opportunity for ongoing counseling and support. The approach has yielded significant benefits to the primary caregiver, the person with the illness and to family members. The intervention is now being offered and evaluated in communities across the country.

Background & History

The NYU Center of Excellence on Brain Aging was formed by the NYU's School of Medicine in 2008. Its mission is to translate knowledge of brain aging, Alzheimer's disease (AD), and related disorders into effective strategies for early diagnosis and treatment; to promote healthy aging and to deter cognitive decline. The NYU-CoE has pioneered in scientific discovery and providing clinical treatment using state-of-the-art methodologies and psychosocial interventions. The NYU-CoE encompasses the NIH-funded NYU-Alzheimer's Disease Center (NYU-ADC). *The Psychosocial Research and Support Program of the NYU-CoE* has two goals: (1) to conduct cutting-edge psychosocial intervention research; and (2) to educate the public and scientific community about the importance of psychosocial interventions in optimal comprehensive care. The program collaborates with other researchers at the NYU/CoE and elsewhere to provide a multidisciplinary approach that assesses multiple domains of risk factors and outcome. The program builds on unique capabilities developed over the past two decades, during which NYU was the site of the longest running, largest intervention for family caregivers of people with dementia—the *NYU Caregiver Intervention (NYUCI)*. The program has grown in scope to include psychosocial interventions for people with Mild Cognitive Impairment (MCI) and dementia,

and forged national and international research collaborations and partnerships with community agencies to conduct translational research evaluating the effectiveness of our evidence-based interventions in real world settings.

Program Goals

NYUCI was designed to improve caregiving skills, mobilize the support of naturally existing family networks, and provide counseling as needed over the entire course of caring for a spouse with dementia. The approach, which has been documented in numerous research reports, has yielded significant benefits to the primary caregiver, the person with dementia and to family members.

Program Description

The NYUCI includes six sessions of individual and family counseling, support group participation, and additional counseling by telephone for the primary caregiver and family members. Each caregiver receives *all* components of the intervention, and is provided with ad hoc phone/email support for an indefinite period of time. A detailed intake assessment and interview as well as periodic follow-ups, guide the counseling.

The *first component* consists of two individual and four family counseling sessions that include relatives suggested by the caregiver (in the original NYUCI, the person with dementia was not included, although in some implementations, this is no longer the case). The content of these sessions is determined by a needs assessment of each caregiver and other participating family members (e.g., learning techniques for management of behavioral issues, and promoting communication among family members). Counselors also provided education about AD and community resources. The *second component* of the intervention is participation in a support group to provide the caregiver with continuous emotional support and education. The *third component* of the program is "ad hoc" counseling—the continuous availability of counselors to caregivers and families to help them deal with crises and with the changing nature and severity of their relatives' symptoms over the course of the disease. The emergence of new psychiatric and behavioral symptoms, or difficulties with ADLs, often precipitated ad hoc calls from caregivers. Ad hoc counseling makes it possible for caregivers and families to determine the amount

of contact they have with the counselors beyond the scheduled structured sessions.

Program Evaluation

The randomized controlled trial of the NYUCI began in 1987. Over a period of 9.5 years, 406 spouse caregivers were enrolled in the study, of whom half (206) received the intervention and half received usual care. All caregivers were interviewed at intake and every four months during the first year and every six months thereafter, by telephone or in person, using the comprehensive battery of structured questionnaires first administered at intake.

Counselors at NYU who implemented the original NYUCI had masters' degrees in a health or social service related field (social work, psychology, gerontology or counseling) who met weekly with the Principle Investigator, Dr. Mittelman. They all implemented the structure of the intervention consistently, all were knowledgeable about AD and caregiving, and they all were able to build on the positive aspects of the family interactions and reduce conflicts, albeit in different ways.

The NYUCI served more than 400 spouse caregivers and their family members in the original study and through collaborations with community organizations and researchers from diverse areas. The "3 Country Study," conducted in the US, England and Australia, enrolled 154 caregivers whose spouses all received donepezil; half the caregivers selected at random, received the NYUCI. Community translations of the intervention in Minnesota, Vermont and Medicaid Managed Care in NYC have served more than 100 caregivers and new community sites around the country are currently enrolling additional caregivers. In the original NYUCI, each counselor was responsible for more than 50 families. An independent evaluation of the first community translation in Minnesota, which began in 2007, estimated that the direct service costs per caregiver would be between \$850 and \$1430 with an average cost of \$1,226.

Replication

The outcomes achieved by the NYUCI have brought it to the attention of many states and funding sources that wish to make its valuable benefits widely available. Translations into community settings have

been implemented in Minnesota since 2007, and are beginning in California and Georgia with funding from the Administration on Aging. NYUCI replication involves active ongoing relationships between the original researchers and the community sites. The research partner provides in person training, followed by regular ongoing training and support by phone and internet to assure fidelity to the original, and collaborates in evaluation of the results, while the community partner provides the intervention. All sites are using computerized databases to track all aspects of the intervention. The Minnesota translation is using direct data entry for all caregiver assessments.

Diversity

While the majority of the recipients of the original NYUCI were Caucasian, the content of the intervention depends on the needs of each individual caregiver and family member, making it applicable to families from diverse racial and ethnic backgrounds. A replication in northern Manhattan demonstrated its feasibility for Latino caregivers. In Minnesota, the intervention has been effective in rural as well as urban settings. AoA translations funded in 2009 in California and Georgia will focus specifically on caregivers of diverse backgrounds, including Chinese, Japanese, Latinos and African Americans. Requests for training materials have been received from around the world, and plans are currently underway for multiple language translations in the coming years.

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National Family Caregiving Awards

Ride Partners and Repairs with Care

Partners in Care, Inc.
Pasadena, Maryland



Partners In Care Maryland empowers older adults to remain independent in their own homes through a time-exchange network where assistance is available to older adults and their caregivers for neighborly tasks such as transportation and household repairs, thus enabling all participants to contribute to the well-being of each other.

Background & History

Partners In Care (PIC) is a community nonprofit, the brainchild of three local women who wanted to not only create a program that helps older adults to remain in the homes that they love, but also to honor the abundance of gifts and talents that older adults can offer to the community. Finishing their Masters programs in gerontology and/or healthcare administration, the vision of the PIC's founders in 1993 was to engage community participants across geographic boundaries to help as many older adults as possible to remain independent in their homes and simultaneously to provide help and relief to their caregivers. After research on the concept of reciprocity, planning of the program's architecture, and finding support in the community, the time exchange started 18 years ago with 26 people helping each other with transportation and handyman assistance.

Program Goals

The goal of the program is to create a virtual network of neighborly care for older adults who wish to remain in their homes and for the people who care for them. By mapping the gifts and talents of all members and creating a flexible structure where each person can ask for help or can contribute what they would like, the program fills a very important niche to the menu of services available to older adults and their caregivers. Although the program is continuously evolving, growth each year, both in the number of members and the numbers of services provided, and the creation of additional geographic sites are indications that the program is successful.

Program Description

What happens when we become too old or frail to drive to the grocery store or the doctor's office or to make even the simplest repairs at home? What if our caregivers are overwhelmed? In keeping with its mission to help older adults remain in their homes, PIC recruits participants from the community to help each other with a variety of non-medical tasks. For example, more than 400 members volunteer to use their own cars to provide no-monetary-cost rides to the doctor and to the grocery store. Other members volunteer services such as handyman repairs. Still others volunteer to be part of the teams that interview new members in their homes, be part of the service matchmaking process, or provide one-on-one advocacy and resource referral. PIC's arm-in-arm, door-to-door, kind, patient, neighborly service has been a life-saver for both older adults and many beleaguered caregivers who can rely on and trust PIC volunteers to transport their loved one, wait with them, and bring them safely home again, often stopping for prescriptions or groceries along the way.

The program is modeled on an innovative concept called "time exchange." Participants earn one "credit" for every hour spent assisting others. Those participants then use those credits to "pay" for services they themselves need or they donate their credits to others or to the general bank for individuals who are not able to earn hours. Caregivers may choose to help others while others are helping their loved ones. Everyone gets a chance for a change of pace and the opportunity to meet new people. At the same time, those who receive services are not made to feel as if they are accepting charity. All recipients are encouraged to "give back" according to the talents they possess. For some frail members, giving a small donation once a year puts a "credit" in their "bank" and gives them the confidence to ask for rides or handyman help whenever they need a service. For example, someone who can no longer drive and needs rides may contribute their expertise in business or accounting, or help with PIC's monthly telephone surveys, or have friendly visits with lonely individuals via telephone or do translation or cooking and baking for PIC's social events. Others may choose to contribute items to the PIC Resale Boutique which helps support the program or to work in the boutique (with their transportation provided by other volunteers).

Timeline

Approximately two years were needed for planning and design before the original program was launched in 1993. The first steps included research on cultural reciprocity and on previous initiatives, including pilot “service-credit-exchange” sites funded by Robert Wood Johnson and writings about *Time Dollars*. Several site visits were made and then a program was designed, specific to the mission of helping older adults age in community. That plan was incorporated into grant requests, one of which funded the initial start.

Financial Issues

Approximately \$60,000 was required to start the program in 1993. The program has found that each new program or separate site requires between \$60,000 and \$75,000 depending on location and planned activities. Sources of funding are diverse with grant funding making up approximately 40% of the budget. Social enterprises, such as the thrift store, make up approximately 30%, and the remainder is community support through fundraisers and individual gifts.

Staffing

At the outset, one full time equivalent was required for initial community outreach, member recruitment and retention, and service matching. Staffing needs changed over time with growth of each program or site and as new initiatives are implemented. The program currently has seven full-time and six part-time employees.

Partners

Long time partners include the Area Agency on Aging in each location, as many of the services we provide are a niche to the menu already offered by these entities, and resource referral is reciprocal. The VISTA and AmeriCorps programs have also been long time partners, offering an excellent opportunity to staff start-up programs. The program has had a long term partnership with the state transportation office as it is able to provide niche transportation for older adults who are not able to utilize public transits. The program also partners continually with local churches, service groups, high schools, community colleges, and universities, although these change over time.

Outreach

PIC’s partnership with the Area Agency on Aging allows the staff to directly communicate with the caregiver program and to be one of many resources on their referral list. The program has had good success with local media, speaking engagements to a variety of groups, and word of mouth referrals from the members.

Diversity

PIC provides no-monetary-cost services to older adults, men and women (50-plus) and their caregivers. The population is ethnically and racially diverse, and generally reflects the community population as a whole. Approximately 40% of PIC’s members have incomes of \$1000 per month or less; however, as long as they meet the age requirement, anyone of any race, gender, and income in the counties can receive PIC services. The only requirements is that they must be older adults and that they agree to be interviewed in their home so that the program can be clearly explained to them and that they agree to be members of the time exchange.

Challenges & Barriers

Current challenges center on the fragile economy, resulting in less support from government and traditional philanthropic resources while trying to meet increased demand. It is an ongoing and serious challenge. The program has created groups of leadership volunteers to try supplement efforts that are no longer funded by grants. The program staff is also looking at new social enterprises which may help support the program.

Program Evaluation

A survey of the entire membership was just completed in May 2011. While there is preliminary data, a report is currently being completed. Visit www.partnersincare.org for more information.

Lessons Learned

The program has learned many lessons during its eighteen years. Perhaps two of the most useful are diversification of funding streams and the importance of creating partnerships which enhance the mission.

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Caregiver Connection Telephone Support Groups

Senior Services of Albany
Albany, New York



Caregiver Connection Telephone Support Groups enhance the effectiveness, accessibility and reach of a mainstay of caregiver support—the support group—by delivering an evidence-based program to family caregivers who are connected by telephone conference call.

Background & History

Senior Services of Albany (SSA), a non-profit organization based in Albany, New York, has been enabling seniors to remain in the community for 58 years. SSA's programs (e.g., nutrition, transportation, adult day care, caregiver support & wellness) serve over 5,000 individuals annually. SSA received a grant from the Administration on Aging (AoA) National Family Caregiver Support Program in late 2001 to develop and test a new approach to caregiver support, Telephone Support Groups (TSG). SSA's history of caregiver services started in the late 1980's through a contract with a national employee assistance program company. With the advent of Title III-E Older Americans Act funds, SSA developed a comprehensive caregiver support program, *The Caregiver Connection* (TCC) in 2003.

Program Goals

The goal of Caregiver Connection TSG is to enhance the effectiveness, accessibility and reach of caregiver support groups by delivering an evidence-based program to family caregivers who are connected by telephone conference call. SSA has statistically significant outcomes data for TSG and has eliminated or reduced many barriers to support group participation through telephone delivery. Most of the individuals who have been in these groups would not otherwise be able to attend an in-person group. Examples include caregivers who live in rural areas or are unable to leave their loved one alone, or are disabled themselves.

Program Description

TSG are 12-session psycho-educational support

groups for family caregivers which meet via telephone conference call. This evidence-based professionally led support program connects family caregivers while each is in the comfort and convenience of their own home. Currently SSA offers this program as a "12 Week Tune-up" which meets in the evenings weekly for 12 weeks. A recent compliment to the support group meetings are Tele-Seminars; one-time topical informational presentations also held by evening teleconference. Tele-seminars have included: "Understanding Depression," "Legal Tools for Caregivers," and "Bringing Services into the Home."

It is the uncommon pairing of two common entities, the support group and conference call technology, which makes TSG special. The conference call technology used for TSG is very effective, while at the same time inexpensive and user-friendly. Because caregivers are often overburdened and may be uncomfortable with technology, a leader-as-operator model is used where the leader dials out to each member to initiate the meeting and monitors the call via a webpage. Participants never navigate an automated system, have a charge on their phone bill, nor need special equipment. Through these efforts, professionally led support groups become accessible to those who cannot attend in-person groups, such as an 80 year old woman who is legally blind, but caring for her immobile husband who has Parkinson's disease. The flexibility of the technology also allows a daughter to attend a meeting on her cell phone while in the lounge of the hospital where her mother has been admitted or a spouse who travels south for the winter to continue to attend the same group with familiar members.

TSG are the only program in the Albany, NY area, and one of few in the country offering caregiver support groups or seminars by teleconference. Since 2002 a total of 27 TSG groups (each meeting 12 times) have been offered, serving over 135 caregivers, of which 30% were spouses and 70% were adult children. Approximately 50% have been caring for a loved one with Alzheimer's disease or related dementia. About 25% of the caregivers have been from rural areas and 8% have identified with minority ethnic groups.

Timeline

As a demonstration project with a research component, our timeline would differ from the timeline of replicators. An agency seeking to replicate should allow

3-6 months for staff training, getting materials ready and developing and implementing marketing before the first participants are registered. This timeframe would be adjusted depending on agency experience with population and similar programs as well as amount of staff time devoted to project. The timeline of securing funding for this new program is another matter and will vary depending on funding cycles and success or ability to reallocate funds from underutilized programs.

Financial Issues

The funding for our initial demonstration/research project would vary widely from the funding needed to replicate the project. Our current program is funded by Older Americans Act Title III-E funds and a United Way investment. The cost per meeting can be expected to be \$200-\$300 depending on conference call per-minute rate and amount of time the leader spends between-meetings on individual follow-up, planning, marketing, registration etc. We have experienced a reduction in funding from the Area Agency on Aging; program has been sustained without reduction in service due to United Way investment. However the future of that investment is uncertain.

Staffing

Most tasks associated with the TSG program are conducted independently by the social worker/leader. The program operates within, and receives support from the broader caregiver program at the agency, and the department in which it is housed. The TSGs and Tele-Seminars are led by the agency’s Licensed Clinical Social Worker who has been leading such groups since 2002. Other services of the TCC program are handled by the ElderCare Counselor, a full-time human services professional. Supervision, reporting and contracts are the responsibility of the agency’s Director of Community Care Services. Total staff time is approximately 1.5 full time equivalents. Staff time is dependent upon the number of groups run annually and extent of evaluation.

Partners

SSA’s original three-year grant funded TSG project was developed, supervised and evaluated with the University at Albany Institute of Gerontology. Current TSGs are offered as part of SSA’s TCC program through a contract with the Albany County Department for Aging

(Older Americans Act Title III-E funds). A dementia-specific TSG was developed and co-led in 2007 with the Alzheimer’s Association. The local United Way has selected the program to receive an investment for the past three community investment cycles. SSA has collaborated with the Capital District Gay and Lesbian Community Council to offer a Tele-Seminar tailored to the needs of LGBT caregivers

Outreach

Marketing/outreach includes community presence at events via information tables, local newspaper announcements, flyers, email, website, and external and internal referrals.

Diversity

TSG have assisted long-distance, same-household, spousal, LGBT, sandwich generation, professional and working class caregivers. Many barriers to Support Group participation are eliminated or reduced by offering the groups via telephone, including issues of transportation, distance, child or elder care and discomfort in face-to-face groups. Participating from the safe comfort of home allows for participation without intimidation due to skin color, wardrobe, physical disability etc. Albany County and the Capital Region quickly transitions from urban to suburban to rural; all these populations are reached and served through TSGs. SSA has recently partnered with the Capital District Gay and Lesbian Community Council to better serve LGBT caregivers. It is possible, through Telephone Support Groups, to serve broad areas with groups tailored to different needs such as language, male caregivers, and LGBT caregivers.

Challenges & Barriers

Replicating agencies could expect challenges in the following areas: securing new sources of funding, educating referral sources and potential participants about a new program, clearing-up misconceptions about the technology and identifying a leader who is a good fit to the model and mode of delivery.

Program Evaluation

The results of our AoA funded evaluation of TSG’s indicated strong positive effects for adult children. Participants were randomly assigned to either be in the TSG or a waiting list condition and completed a

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series of standardized instruments before and after their time in the TSG or waiting. Adult children in TSG had increases in positive social interaction and emotional/informational support, effectiveness, knowledge of services, how to access services, and use of services. Adult child caregivers also had decreases in stress, strain and depression rates.¹ More details about the evaluation of this program are available at www.seniorservicesofalbany.com/aoa.htm.

Lessons Learned

- Marketing is important. No one will seek out or refer to a program that they never imagined or expected would exist. The first thing you have to do is educate others.
- Clearing up misconceptions about ‘conference calls’ is important. Those unfamiliar with them, or who have had bad experiences, will not recognize TSG as an option.
- Having a facilitator who is comfortable with the technology and lack of visual cues is important. Leading a group over the telephone differs from leading one in-person.
- The structure of the psycho-educational model, with a set of 12 weekly agendas to follow, not only helps you to deliver an effective group, but the structure makes facilitating a group over the telephone much easier.

Contact

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1. Smith T and Toseland R. (2006). The effectiveness of a telephone support program for caregivers of frail older adults. *The Gerontologist*;46(5):620-9.

Connections: An Innovative Home-Based Activity Program

Alzheimer’s Association, Central & Western Virginia Chapter
Charlottesville, Virginia

alzheimer’s association™

Connections: Home-Based Activity Programming for Persons with Dementia provides caregivers with strategies needed to interact positively with the individual diagnosed with dementia; help the individual remain engaged in life; reduce behavioral symptoms; and connect families to a full range of community supports leading to increased caregiver confidence and support.

Background & History

The Alzheimer’s Association, Central and Western VA, and the University of Virginia developed a home-based intervention and Activities Guide called *Connections* after hearing feedback from families that they needed help at home. Coordination between the Alzheimer’s Association, the University students and the families is key to the success of the program. The University of Virginia School of Nursing and Speech and Communications departments were committed to working closely with the Alzheimer’s Association. Students were trained in the *Connections* program, and in *Dementia Basics* by the Alzheimer’s Association.

Program Goals

The goal of the program is to improve the quality of life for caregivers and persons diagnosed with Alzheimer’s disease and related disorders (ADRD) through a “partnered volunteer” in-home intervention offering strategies, support, and education to caregivers for the set up and implementation of meaningful activities for persons with ADRD. A second goal of the program is to offer solutions that will enhance care in the home and delay or prevent institutionalization.

Program Description

The *Connections* Program is an evidenced informed, caregiver supportive intervention, justified by substantive research conducted by the Alzheimer’s Association Central & Western VA Chapter and the University of Virginia. In collaboration, staff designed

and tested an innovative activities program and toolkit utilizing student volunteers and combining the principles of Montessori Based Programming for Persons with Dementia™, therapeutic recreation, and cognitive intervention

The program consists of the following components:

- The Connections Activities Guide, an easy to use, step by step, color coded guidebook to activity engagement
- An eight-week series of home visits by staff and university students
- The concept of “partnered volunteering” in which the student and the caregiver work as a team to engage the person with dementia in meaningful activities adapted to his/her functional level and interests.

The program teaches caregivers how to modify the home environment, set up meaningful and appropriate activities and use guided intervention techniques. The program is considered strength-based, incorporating the relative strengths of the individual into the intervention. The toolkit provides simple, easy to use tools that can be individualized for each family. The tools include a chart to help identify where the individual is in the disease progression, conversation starters, a comprehensive leisure interest survey and a color coded cognitive function checklist with matching intervention guide. The toolkit also comes with a resource guide for additional ideas and support.

Activity programming refers to meaningful engagement in activity for the person with dementia. Meaningful activity is determined based on the individuals past interests, current strengths, and/or education level; and is reported as enjoyable to the individual. Examples of meaningful activity are gardening, playing cards, baking, going for walks, or even making the morning coffee. Appropriate activities are adapted and structured using a Montessori and therapeutic recreation-based method. This unique method provides opportunities for persons with dementia to meaningfully interact with the environment while respecting the individual’s long-standing interest.

After the initial consultation visit, the home environment is modified by setting up two to three Activity Centers with input from the participant and caregiver. An Activity Center is a location in

the participant’s home that houses all materials for engagement in a certain activity. For example, if the participant and caregiver selected the activity to “make the morning coffee,” a counter space would be organized and made aesthetically pleasing to direct the participant’s attention to the center. Additionally, if the participant and caregiver select “folding laundry,” an inviting space by an easy chair would be designated as the Activity Center and laundry baskets would be stacked by the chair with a written reminder.

Timeline

Program planning and implementation phase begins with outreach and marketing, recruiting home-visitors, and training over a period of 6-12 months.

Financial Issues

The program began five years ago, with the first research funding awarded in 2008 by the University of Virginia as part of the Academic Community Engagement program. In 2009, the project was awarded a \$37,000 grant from the Alzheimer’s and Related Diseases Research Award Fund (ARDRAF) and was accepted by the International Conference on Alzheimer’s disease (ICAD) as a poster session in July 2010. The project has been awarded \$250,000 by the U.S. Administration on Aging to replicate in five rural counties in Virginia; this award also involves research focusing on the efficacy of the program.

Staffing

The program was staffed at the Alzheimer’s Association and the Area Agency on Aging work closely to manage the program. Initially the program utilized student volunteers; however, the model is changing to train staff at the Area Agencies on Aging as Home Visit Interventionists.

Partners

Partners for the program are Rappahannock-Rapidan Community Services Board; University of Virginia; and Aging Together.

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Outreach

Marketing and public relations outreach has been targeted and directed through print materials, TV, and radio, and through community health fairs. Caregivers calling any senior agencies in the area are informed about the program.

Diversity

Outreach to rural faith-based communities has been a strategy of the marketing plan that reaches a diverse population.

Program Evaluation

The program is currently being evaluated through a rigorous research project with the University of Virginia.

Lessons Learned

One of the lessons learned is that training the Home Visitors does take time and, there is a learning curve. Working closely with partner agencies is a key to program success.

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ThisCaringHome.org:

A Web Tool for Assisting Alzheimer's Caregivers Online

Weill Cornell Medical College
New York, New York



ThisCaringHome.org, a new interactive multimedia website, offers caregivers innovative ways to learn research-based strategies that reduce caregiver stress and enhance the safety and well-being of their loved ones with Alzheimer's disease or other types of dementia.

Background & History

The developers of ThisCaringHome.org believed that a multimedia caregiver e-learning tool was more effective at educating caregivers about complex safety and care issues than text-based standard home safety checklists. The Weill Cornell Medical College (WCMC) of Cornell University, affiliated with New York-Presbyterian Hospital, and its Division of Geriatrics is dedicated to serving the physical, social, mental health, and environmental needs of older adults. Rosemary Bakker, the developer of ThisCaringHome.org, is a gerontologist, certified interior designer, dementia specialist and former caregiver to her mother who had Alzheimer's disease; she is on academic staff and is the Leader of Caregiver Services in WCMC's Division of Geriatrics.

Program Goals

Among our goals were to increase the positive rewards of caregiving and help caregivers keep their loved ones living at home. To assess the benefits of ThisCaringHome.org (TCH), an online research tool was developed and administered to 25 family caregivers. During a six-month period, caregivers were asked to view the website for a minimum of 10-minutes every month, read a weekly email tip that is a standard feature of TCH, and complete online questionnaires at the beginning, at three months, and at six-months. Almost two thirds of caregivers (n=25) scored higher on the Positive Aspects of Caregiving Scale (PAC), with a total overall 74% increase in the baseline score. Caregiving literature suggests that the positive aspects of

caregiving, where the caregiver experiences their role as satisfying and rewarding, can help balance the stresses of caregiving.

Program Description

ThisCaringHome.org, a graphics-rich interactive website, shows how best to adapt a home for persons with Alzheimer's disease and related disorders. A unique aspect of this website is its Virtual Home Safety section that allows visitors to explore research-based solutions to home safety and daily care issues by a simple mouse click over a room in the house. Visitors can view animated caregivers and persons with Alzheimer's using safety features such as grab bars and stove turn off devices.

The website also provides information to help the person with Alzheimer's disease live a healthier, more meaningful life. With over 50 videos, 30 animations, 300 photographs, and numerous product listings and consumer guides, this 350 page multimedia website offers inspiring educational materials for caregivers with diverse learning needs.

Timeline

The project took over four years to complete with major steps being: review initial project plan and activities; develop institutional review board focus group protocols; solicit advisory board members; review literature; develop topic outline and send for Advisory Board review; quality assurance testing of virtual home; hold focus groups; develop senior friendly format; conduct production meetings with web team; develop online surveys; update resource list; implement online surveys; complete launch of virtual home; training and marketing; analyzing surveys; add updates and troubleshooting.

Financial Issues

The project was completed over a four year period at the cost of approximately \$750,000 from various foundations. Securing ongoing funding has been a challenge. The National Family Caregiving Award helped pay for research updates and web fees. Updating 350 pages of web material is a challenge in this economic climate; the developers are looking for new sources of revenue on an ongoing basis, including applying for awards.

Staffing

The Project Director updates all the research and uses a web company to make the needed changes. As Alzheimer's care requires a team approach, an Advisory Board of 14 experts, including social workers, dementia specialists, nurses, and physical and occupational therapists provided reviews of all key facts and recommendations at the outset. The program is hoping to work with the Alzheimer's Association's staff on maintaining the website and the research.

Partners

The program has a request in to the Alzheimer's Association to be a sponsor and to help the program head up a message board for caregivers to provide individual consultations to caregivers

Outreach

Public speaking is done at various agencies and organizations in New York City, including the Alzheimer's Association.

Diversity

The developers incorporated the Alzheimer's Association's recommendations from "*Ten Steps to Providing Culturally Sensitive Dementia Care*." The global idea is to stress the uniqueness of each person and caregiving situation and offer a variety of suggestions to caregiving problems. To represent the multicultural backgrounds of visitors to the site, photographs of caregivers from diverse backgrounds were used, including Asian, Hispanic, and African American. A medium tone skin color was used for the animated characters. African American and Hispanic families seek support from their faith community and the developers present TCH through Cornell Telehealth conferences to reach these religious audiences. In part to address cultural beliefs that attribute the symptoms of cognitive impairment to normal aging or to sin, a section on "What is Dementia?" was included.

Challenges & Barriers

Ongoing funding is always a challenge. Securing corporate or grant funding has been more of a challenge than anticipated due to the recession. Major corporations and foundations have been approached for site sponsorship. Also TCH's server was attacked by a

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malicious virus and the website was shut down for three weeks. Although most of the information was recovered, the Forum/Message Board was destroyed. Due to lack of funding, this feature was not redeveloped. The Forum was considered critical to the success of the project as it allowed the Project Director to give direct advice to caregivers and caregivers to interact and share their experiences with one other.

Program Evaluation

In addition to the pilot study, an online survey of 150 TCH users was conducted with the following results:

- Helpfulness in finding the information that you were looking for:
 - 74% Extremely or very helpful, 19% Somewhat helpful, and 2% Not very helpful
- Usefulness of the information provided on this site:
 - 79% Extremely or very helpful, 16% Somewhat helpful, 2% Not very helpful
- Overall level of satisfaction with ThisCaringHome:
 - 82% Extremely or very helpful and 16% Somewhat helpful
- Helpfulness of ThisCaringHome in improving your caregiving skills:
 - 55% Extremely or very helpful, 30% Somewhat helpful, 2% Not very helpful, 13.0% not applicable
- Helpfulness of ThisCaringHome in improving your caregiving skills in the future:
 - 69% Extremely or very helpful, 26% Somewhat helpful, and 6% Not applicable
- Likelihood of your using ThisCaringHome as an ongoing information resource:
 - 85% Extremely or very likely, and 13% Somewhat likely, 1% Not very likely

The return rate of the online survey participants was high; 52% of participants had used THC a minimum of four times and 19% had one to three visits. Survey statistics: 150 caregivers from 29 states; 37% adult child caregivers, 35% spouses, 14% health care providers.

Lessons Learned

This project grew quite ambitiously over the development period due to focus group feedback; caregivers requested more animated features on the virtual characters. It was decided that in the long run that it was worth responding to this request. Since the developers redid all their animations and did not use their existing prototype figures from a former project as originally planned, it took longer than expected to complete the project, with far more work and more corrections than anticipated.

Additionally, caregivers requested more product information and the developers began product testing to identify potential problems in their use by people with dementia and their caregivers, who may have physical limitations due to age-related health conditions. For example, a sliding seat transfer bench advertised as follows: “effortlessly sliding back and forth, any physical strain on the user or helper is minimized.” While TCH agreed that it is easier to help a person transfer into a tub using a sliding seat, they were shocked at how much physical effort is still required to slide the seat with the person sitting in it. Consequently, This Caring Home’s Expert Review now cautions caregivers that back injury can still occur using this product and remind them of the importance of using proper body mechanics (with links to information on correct posture).

It is important to respond as needed and change course due to the user’s feedback, but one has to be careful that it does not bog the project down. In THC’s case, the result is an award winning website, with more user-friendly and inviting visuals of the home environment with high a high return rate.

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Translation of ESP/Skills2Care

Fox GERI: Geriatric Education & Research Institute
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*The translation of ESP/
Skills2Care is a collaborative
project bridging the gap
between an evidence-based
program for caregivers of people
with dementia developed in
the research environment,
and the provision of those*

*interventions by occupational therapists in a sustainable
reimbursement environment.*

Background & History

Fox GERI: Geriatric Education & Research Institute was founded in 2007 as a not-for-profit company whose mission is to provide high quality educational services to the public on health care related issues important to the geriatric population and to advance the fields of geriatric rehabilitation and medicine through education of health care professionals and collaborative research.

Translation of proven caregiver programs generally focuses on training care managers or social workers for delivery in the aging service network, the Veterans Administration, or hospital discharge services. Few evidence-based caregiver programs have not been translated for delivery in settings such as homecare nor involved training health professionals who routinely are in contact with families of dementia patients. Furthermore, translational efforts have been supported partially by grant mechanisms sponsored by government agencies and foundations. However, it is unclear whether existing reimbursement mechanisms can support delivery and sustainability of proven caregiver programs.

This innovative program is the translation of the Environmental Skill-building Program/Skills2Care for delivery by occupational therapists (OTs) in a private practice, Fox Rehabilitation, which provides house calls using Medicare Part B reimbursement. This is the first translational effort that involves integrating an evidence-based caregiver intervention into a large private homecare practice as part of routine therapeutic services provided to dementia patients and their caregivers through Medicare Part B. All Skills2Care sessions have been reimbursed by the Medicare Part B carrier, demonstrating sustainability within existing

reimbursement streams. The program is innovative in that this is the first evidence-based caregiver program that has a sustainable funding source. Having demonstrated initial success with 23 OTs implementing Skills2Care, the continuation of scaling the program up to all 140+ OTs employed by Fox Rehabilitation is ongoing.

Program Goals

The ongoing goals of the program are to: translate an evidence-based practice into on-going OT therapeutic service delivery; provide OTs with needed skills to effectively treat persons with dementia and their caregivers; provide caregivers access to supportive services, education and address unmet needs; elevate the entire practice of Fox as it concerns treating patients with dementia and their caregivers and demonstrate the ability for reimbursement by Medicare Part B.

Program Description

The project described here is the translation of the Environmental Skill-building Program/Skills2Care for delivery by occupational therapists (OTs) in a private practice, Fox Rehabilitation, which provides house calls using Medicare Part B reimbursement. Skills2Care as tested by the National Institutes of Health Resources to Enhance Alzheimer's Caregivers Health (REACH I) and subsequent randomized trials, provides caregivers with specific knowledge and skills to support daily function and manage neuropsychiatric behaviors of dementia patients, enhance home safety, and alleviate caregiver upset and care concerns (Gitlin, Winter, Corcoran, Dennis, Schinfeld & Hauck, 2003; Gitlin et al., 2001). Skills2Care meets Medicare Part B reimbursement requirements as it links caregiver training to patient functional goals. Thus, there is potential to sustain delivery through this funding mechanism.

Skills2Care involves up to eight home sessions over four months by OTs who assess specific needs, concerns and challenges of caregivers, the physical and social environment, caregiver management approaches and dementia patient functionality. The program is based on assessments and prioritization of caregiver-identified concerns (e.g., resistance to care), therapists tailor disease education, provide instruction in problem-solving and strategies. Strategies introduced include environmental simplification (e.g., de-cluttering, safety proofing), communication (e.g., tactile, verbal cueing),

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task simplification, engaging patient in activities, and stress reduction. Findings show that Skills2Care reduces frequency of behavioral symptoms and functional decline in dementia patients, reduces caregiver upset, reduces need for assistance from others; and improves caregiver skill, efficacy and mood. The visit schedule and number of sessions are flexible, although a minimum of three is recommended.

Timeline

This innovative project began in 2007 with a two year translational phase, is currently ongoing through the full implementation stage. Five key activities were necessary to integrate Skills2Care: (1) intervention refinements (2 yrs) (2) preparing for implementation (2 yrs) (3) establishing training (2 yrs + ongoing) (4) establishing referral mechanisms (ongoing from initiation of project) (5) evaluation process (ongoing from initiation of project).

Financial Issues

The budget for the program was divided into two phases: the translational phase and the implementation phase. The total budget for the translational phase which included costs for all three members of the collaborative team was \$241,000.00. This phase was partially funded by a grant from the Rosalynn Carter Institute/Johnson & Johnson Caregivers Program Demonstration Projects. The budget for the implementation phase includes \$2,000 in training fees per OT as well as revenue lost during the training sessions and salary cost of project managers/coordinators and is projected to be \$500,000 over the next five years.

All Skills2Care sessions have been reimbursed by the Medicare Part B carrier, demonstrating sustainability within existing reimbursement streams. However changes to the Medicare reimbursement system, may affect the program in the future. Having demonstrated success with 23 OTs implementing ESP, the continuation of scaling the program up to all 140+ Fox Rehabilitation OTs is ongoing.

Staffing

A dedicated project manager within the Fox Occupational Therapy Clinical Services Department directly oversees all aspects of the program. Statistics are collected weekly and data is reviewed weekly, monthly

and quarterly by the program manager, other clinical leaders and business management team members, to ensure that the program is moving forward and meeting targets. If the program does not meet expected statistical results or does not meet the broader goals of the program, steps are taken to identify and rectify the cause(s). If the project is exceeding expectations, then steps are taken to identify and repeat the cause(s) of the positive outcomes.

At its most basic level, to deliver Skills2Care requires one registered OT to be trained and certified in the intervention. However, as the project was originally designed with the intent for a large scale up and long term sustainability, project staff included a Fox GERI project manager who coordinated the collaboration between the research team and the practice site. No new staff was hired specifically for this program. Existing staff at Fox Rehabilitation required additional trainings specific to this project. Staff who received training included representatives from the clinical team of occupational and physical therapists, quality assurance team, billing department, reimbursement department, intake department, and marketing division. All staff have appropriate credentials for their departments. The billing data from Skills2Care is integrated into Fox Rehabilitation's electronic medical billing systems and will be incorporated into the new electronic health record currently in development and being implemented company wide.

Partners

When the project began, a strong collaboration was created among (1) the original research team who developed Skills2Care: Laura Gitlin, PhD and her colleagues at the Jefferson Center for Applied Research on Aging and Health (2) Fox GERI and (3) the practice site, Fox Rehabilitation. Specific goals for the collaboration as well as a clear definition of contributing member's roles and responsibilities assured a productive and effective team. The original research team provided training and ensured fidelity to the original intervention. Fox GERI served to bridge the gap between the research and reimbursable environments by overseeing all aspects of the collaboration and project management. Fox Rehabilitation is the private practice site providing occupational therapy services as well as physical therapy and speech-language pathology services to older adults and their caregivers in their

home through Medicare Part B. Fox Rehabilitation currently employs 140+ OTs in seven states on the east coast. By training OTs delivering home care, there is the opportunity to reach caregivers with unmet needs that have not previously been involved in supportive services or who have access to such services. The partners have not changed.

Outreach

Fox employs a 25+ person marketing team to promote Fox Rehabilitation services, including Skills2Care to physicians, nurses, social workers and other community partners. Promotional materials were created to supplement the marketing efforts. Additionally, caregivers appropriate for Skills2Care are identified by the Fox physical, occupational and speech therapists from their current, existing caseloads. Commonly, patients with dementia are referred to Fox for functional decline, and only after on caseload is the therapist able to identify the caregiver in need. This need is then communicated to the referral source and an appropriate referral to OT and Skills2Care is made.

Diversity

Skills2Care is grounded in five immutable treatment principles: client-centered (areas targeted for intervention are caregiver-identified); problem-solving (caregivers learn how to identify concerns and strategies); tailoring (dose, intensity and strategies are customized to person-environment configurations); action-oriented (caregivers learn skills by practicing with therapists); and cultural relevance (therapists identify values guiding care decisions to assure appropriateness of tailored strategies). As core principles of Skills2Care include a client-centered approach and cultural relevance, the diversity of every individual caregiver is respected and addressed.

Challenges & Barriers

The first challenge involved balancing the training needs of the program with minimizing revenue loss resulting from OTs being pulled from the field. A three-pronged approach to training was developed which included readings, asynchronous web-based modules, and a face-to-face seminar to maximize training and minimize time and revenue loss. As traditional fidelity measures utilized in a randomized controlled trial were not feasible, the second challenge included developing

and adopting adequate fidelity checks within the company's and OT's practices. The third challenge was to adapt Skills2Care to conform to Medicare Part B requirements while maintaining fidelity.

Program Evaluation

The program is evaluated on a weekly, monthly and quarterly basis against established statistical goals and the overarching program goals.

Lessons Learned

Key lessons learned include that a translational phase was diagnostic and necessary prior to full implementation and that translation is very labor intensive and time consuming. Also key was organizational readiness, including supportive leadership, a dedicated project manager, supervisory structures, training support and referral, client tracking and billing infrastructures. Additionally, the timing of the training to coincide with the availability of eligible caregivers to maximize the efficacy of the training was also critical. The final lesson learned was that translation has unforeseen benefits. New systems, protocols and information elevated all aspects of care for the person with dementia within the company.

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Caring for the Caregiver

The Kennedy Center, Inc.
Trumbull, Connecticut



The Kennedy Center's Caring for the Caregiver program is a truly innovative approach to the caregiving concept. Unlike traditional caregiver programs, where the caregiver is identified as the parent who looks after a child with special needs or disabilities, the 'caregiver' is identified as the adult child with cognitive disabilities, who provides assistance for his or her elder family member over the age of 60.

Background & History

Founded in 1951, The Kennedy Center, Inc. is a community based rehabilitation organization offering innovative and comprehensive program services to persons with special needs and disabilities, from birth through their senior years. Founder Evelyn Kennedy established The Kennedy Center as a grassroots organization, with a dozen other parents, all of whom had children with special needs and disabilities. On an annual basis, over 1,900 individuals receive program services through the Center's departments of Rehabilitation Services, Residential Services and Kennedy Industries. The mission is to promote the empowerment of our individuals with diverse abilities, disabilities and experiences toward optimal participation and inclusion in the community.

The Kennedy Center has been a driving force in providing advocacy and services to people with disabilities. Our statewide programs continue to promote independence for people with disabilities. As one of the most inclusive rehabilitation facilities in the state, The Kennedy Center provides a wide variety of service options for children and adults with intellectual disabilities, behavioral health conditions, acquired brain injury, physical disabilities, developmental disabilities, and a variety of other special needs. Through advocacy, self-empowerment, optimal community integration, active planning and participation in all facets of the delivery of services, our consumers reach higher levels of community inclusion and independence.

There was not extensive planning involved in the design of Caring for the Caregiver. It was a logical approach to a concerned family known to the Center.

The Center then searched for a funding source and the Federal Caregiving criteria in the Older Americans Act seemed to be an appropriate match. The Kennedy Center's Caring for the Caregiver program addresses a practical need for families, with a realistic solution that works for consumers. As the life expectancy for individuals with cognitive disabilities increase, in conjunction with the rest of the aging population, more elder parents are becoming less capable of providing care for their family members with special needs. As a result, the Kennedy Center has identified an increasing number of elders seeking support services for their adult children, while dealing with their own aging processes and concerns. The Caring for the Caregiver program is a beneficial alternative for parents who worry about the future of their family members, and their ability to live independently in their own home. The Kennedy Center implemented this pioneering program in logical response to the needs of its consumers and this newly developing trend.

Goals

The Kennedy Center seeks to provide individualized support service for 50 families on an annual basis within the "Caring for the Caregiver" criteria through the following caregiver goals:

- Provide case management
- Address requests from the caregiver for problem solving and decision making
- Provide caregiver support groups
- Provide information and referral services
- Increase consumer functional skills development
- Monitor and evaluate Caregiver programs

Program Description

The Kennedy Center's Caring for the Caregiver program is a truly innovative approach to the caregiving concept. Unlike traditional caregiver programs, where the caregiver is identified as the parent who looks after a child with special needs or disabilities, the 'caregiver' is identified as the adult child with cognitive disabilities, who provides assistance for his or her elder family member over the age of 60.

Caregiver education is the responsibility of the Caregiver Facilitator. Once a family is referred for

service and support, the Caregiver Facilitator conducts a self-paced skill training assessment at the consumer's home. This assessment establishes which skills the caregiver will be taught. The family's input is an integral part of the assessment because it is important that the caregiver with disabilities is taught to complete the task in a manner that complies with the family's common practices, i.e., the way the family has done it in the past. This method ensures a holistic level of comfort for both the caregiver and the parent. During home visits, the Caregiver Facilitator and the Caregiver work on skills such as: cooking, laundering, money managing, vacuuming, dish washing, house cleaning, shopping, and other identified household tasks.

The Family Support Coordinator serves as a vital link in networking caregivers to normal supports as well as the seniors to respite services. The coordination of services is achieved through regular home visits and personal phone contacts. Program services include, but are not limited to case management, counseling, information, referral, functional skill development, respite planning, monitoring and follow-up. Concurrently, both program staff addresses the need of the home's elder adult by providing appropriate service assistance. The Kennedy Center has been serving many of these younger adults since they were children. While the children are grown now, they are living with parents who have become senior citizens. The input and response to the elder family member's concerns is an integral part of the program.

Timeline

The Caregiver Program was established in 2003 as a pilot program and has been consistently funded by the Southwestern CT Agency on Aging. The Center submitted the initial program design and model in the initial application after six weeks of planning and researching to the topic. The Center was notified in August 2003 of funding and hired the staff by October 2003, the initial month of funding and the first referral came that same month.

Financial Issues

The initial funding was from the Southwestern CT Agency on Aging. The amount covered the entire salary of a 25-hour Caregiver Facilitator and partial salary of the Family Support Facilitator. The grant required a 25% cash or in-kind match. Over the past eight years, funding has been obtained from the local United Way, Kraft Foods,

local fundraisers and The Kennedy Center to cover the matching fund amount. The local Agency on Aging funding has been constant, so services have never been interrupted, which has provided stability in the program.

Staffing

The Vice President of Residential Services (full-time staff) is the administrator of the program, and has a Master's Degree in Social Work. Currently, three staff operates the Caregiver program. Only the Family Support Coordinator and the Caregiver Facilitator positions are funded through the program budget. The Family Support Coordinator (part-time staff) has a Bachelor's of Arts Degree in Sociology, and works 15 hours a week for the Caregiver Program. The Caregiver Facilitator (part-time) has a Bachelor's Degree in Psychology/Sociology, and works 30 hours a week for the program. The Caregiver Facilitator manages and provides the direct service for individualized training and maintains the paperwork.

The Family Support Coordinator provides oversight for the plans of service and goals, resources services and information to families. The Family Support Coordinator and Caregiver Facilitator positions have been in place since the inception of the program. Due to a slight funding increase, the Caregiver Facilitator position hours increased from 25 to 30 hours per week.

Partners

The Caring for the Caregiver program works in collaboration with the Southwestern CT Agency on Aging, the Connecticut Department of Developmental Services, and Kennedy Center case management staff as program referral partners. These agencies remain major referral sources, since they work with the target population on a regular basis.

Outreach

The staff are consistently enhancing the working relationship between the Kennedy Center and local Department of Developmental Services Case Managers, through phone calls, emails, meetings and mailings. The program also obtained the services of a 15-hour a week outreach worker through the job employment initiative with the Southwestern CT Area on Aging. This person has been instrumental in expanding outreach efforts.

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Diversity

All participants in the program have a service plan that includes a section on cultural values. The majority of the individuals served are disabled and poor. Staff members are trained to be highly sensitive to all relevant family values. Accordingly, staff receives cultural sensitivity training that specifically addresses the ideals of the wholly diverse service delivery population. Hence, if a diversity issue arises the program protocol requires the Family Support Coordinator to create a team of relevant case managers and appropriate family members, to then determine the best plan for addressing the concern.

Challenges and Barriers

The greatest challenge is convincing the DDS case manager that the program can be an effective and viable program. The solutions to address this perception have been varied. The referral form was simplified to a one-page form, which can be emailed to the Family Support Coordinator. A family who receive services is asked to write a testimonial about the program. This document is shared with the case managers and new families. Additionally, a 4-week Caregiver Educational Series was developed, which provides helpful information so families can expand their support network and increase their knowledge base of potential resources.

Program Evaluation

The Caring for the Caregiver program has shown that with adequate supports and training, parents and their adult children can create successful role reversals that work within the caregiving model. The Kennedy Center measures the effectiveness of the Caregiver program through individualized service plans and consumer satisfaction surveys. The Caregiver Facilitator develops the service plan according to the family's needs and the caregiver's abilities. The service plan establishes reasonable timelines, achievable goals based on the needs of the family and a numerical value for our base line assessments. All service plan goals are individualized, and based on the needs and physical capabilities of the family members. Thus far, according to the aggregate service plans results from 2003 to present, over 70% of consumers have been positively impacted by meeting and/or exceeding their achievable service plan goals.

The Family Support Coordinator is also responsible for the distribution and collection of the annual consumer satisfaction surveys. Both the caregiver and care recipient are asked to respond to survey questions concerning skill development, goal setting strategies and program satisfaction. To date, collected satisfaction surveys have revealed a 100% satisfaction as measured by the established program objectives. Project staffs continue to review all surveys to ensure continuous quality improvements and make any necessary adjustments to the program.

Lessons Learned

It is essential to convince a potential funding source that caregiving support is vital to the community as a whole. The local Agency on Aging should be a viable funding source for the Caregiver Program. The enactment of the Federal National Caregiver Support Program in the Federal Older Americans Act gives priority consideration to older individuals providing care and support to persons with intellectual disabilities and related developmental disabilities.

Home-based services have yielded the best outcomes when addressing caregiver needs. It is important to schedule an initial home visit with a referred family for two reasons. First, it allows staff to see the environment and identify areas of possible support. Second, it helps build a relationship with the family. Once trust has been established between the caregiver and agency worker, the impact can be significant.

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Parent Advocacy Group

Multicultural Community Services (MCS)
of the Pioneer Valley
Springfield, Massachusetts



The Parent Advocacy Group is a group of single elder parents who provide friendship, support, hope and solutions to each other as they advocate for the their sons and daughters

with intellectual challenges.

Background & History

The Parent Advocacy Group (PAG) was developed to meet the needs of single, elder caregivers who had adult sons and daughters with disabilities. The original members resisted the idea of institutionalizing their children, and joining PAG enabled them to keep their family member with a disability at home. PAG offered and continues to offer families the opportunity to work together on behalf of their sons and daughters while planning trainings and social events, advocating for services and providing social support.

MCS of the Pioneer Valley, Inc. is a private, non-profit organization committed to providing culturally and ethically responsive supports that enhance the capacities of individuals with developmental disabilities and their families in order to maximize their quality of life as individuals and as members of the larger community. MCS has provided family support services for three decades; and the work is predicated on the conviction that individuals with disabilities and their families are the program partners. The families have the right and the capacity to define their own service plans; this includes what kinds of supports they receive and how those services are delivered.

MCS has been a pioneer in the Family Support Movement and the programming has grown over the years. The program currently offers families a wide range of service options included in the eight distinct Parent Networking Groups. The program owes its expertise, in large part, to the wisdom of the families with whom it has collaborated. In return for their patience and trust the program has been as responsive as resources and circumstances have allowed. The families lived experience continues to inform the organizational and program development.

Program Goals

The PAG's primary goal is enabling a family member with a disability to remain at home. This goal is accomplished through the following:

- Futures Planning is explored with attorneys who specialize in Guardianship, Wills, Trusts and Estate Planning; and have resulted in some healthy Future's Planning on the part of many members. Family Support Plans or Action Plans are developed with each family and up-dated regularly.
- The Lecture Series is a major part of PAG and offers information on a variety of topics including wellness, future's planning, accessing public benefits, fuel and utility assistance, navigating the DDS System, conflict resolution, self-advocacy, relationships/ sexuality, assistive technology, sibling issues, recreation options, volunteer and work opportunities.
- Monthly Meetings provide the opportunity for support and socialization, education and training, advocacy and social events.
- Collaboration with DDS Service Coordinators ensures that the needs of both parents and individuals are met.
- Service Navigation is driven by the individual needs of each family and available funding.
- Wellness Programs such as diet, exercise, nutrition, preventative medicine are requested and offered regularly—especially with the increase in age of the PAG members.
- Outreach is always a goal as older members pass on, move into assisted living and place their sons and daughters in alternative living situations, etc.

Program Description

The single, elder parents in the PAG are involved in making decisions that affect the group as a whole, as well as having individual control over decisions that affect their family member with a disability. By participating in the PAG, families gain entry into an extensive network of highly connected and resourceful families; and by extension, are able to access personal, professional and even political allies as well. The PAG provides opportunities for more social support, the sharing of practical information, a stronger voice as they

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advocate for services and a wide variety of trainings.

While the Department of Developmental Services (the funder) and MCS maintain governance for these projects, the families (elders) themselves determine the priorities of the group. They assist in evaluating the family advocate, decide on trainings and social activities, conduct fundraising activities, and advocate for needed services and funding.

The guiding values for group membership are: inclusion, acceptance, tolerance, individualism, self-determination and confidentiality. Members are expected to attend group meetings, support activities, complete an annual family satisfaction survey and evaluate the project advocate (Coordinator).

Timeline

The planning and implementation phase of the program took approximately six months with the following steps:

- The first step over a period of two months was to secure the funding. This pilot project was funded by the Massachusetts Department of Developmental Services and hosted by Multicultural Community Services. Financial and program design was put into the hands of the families. Subsequently, families from this underserved group were identified and brought together.
- The second step took place over the next two months and involved exploring the pilot program with single, elder caregivers. This involved exploring the dreams, responsibilities, needs and design of the program as well as settling on a model. The chosen model included developing an annual budget, hiring an advocate, holding monthly meetings and a lecture series, case management and the distribution of stipends.
- The third step over the next two months, involved writing up an advertisement for the recruitment of the advocate, interviewing the advocate (a collaborative effort between MCS and a sub-committee of the families), developing a job description based on the model and hiring the advocate.

Financial Issues

The program is based on a budget of \$40,000: \$20,000 for the advocate position (20 hours per week) and \$20,000 for the families (each of the 20 families

received \$1,000 annually, most of which was used for respite). Historically, this money was sustained through DDS. Due to a decrease in funding in 2011, the National Family Caregiver Award has been critical in sustaining the principle of family-directed services. The Massachusetts Department of Developmental Services, Federal reimbursement, grants from Greater Springfield Senior Services, donations and awards have been other sources of funding. Budget cuts have had tremendous impact on families' ability to control these types of family-directed models. The Caregiver Award enabled the integrity of the project to remain intact. The creative planning and resources of the families still continue.

Staffing

Historically, management of PAG and the other Parent Networking Projects was seen as a partnership between the Massachusetts Department of Developmental Disabilities, MCS and the families. Efforts are constantly being made to reinvigorate these parent networking groups and to reaffirm this partnership. Day to day monitoring of the program, expenses and payroll is done through MCS.

The staff includes a Master's Level Supervisor, a Bachelor's Degree Project Coordinator, and several Direct Care Staff requiring a high school degree and several years of experience in human services. These positions have remained consistent throughout the history of the PAG. However, the numbers of elders in the PAG have fluctuated throughout the years requiring more or less hours of coordination from the coordinator and more or less direct care staff. Recent Family Support budget cuts have also affected the ability to staff the project. Currently, the PAG Coordinator does this coordination along with other agency responsibilities.

Partners

Throughout PAG's history, MCS has collaborated with numerous partners – originating from the individual needs of the families. Among them are Greater Springfield Senior Services around elder services and trainings. Several law offices have offered pro-bono services for issues such as estate planning. The Department of Developmental Services has offered ongoing professional development for staff and a wide variety of trainings for clients. The DDS Office of Learning and Development has offered numerous trainings for staff and families as well, aimed at

family choice and empowerment. Local YMCS's and Jewish Community Centers have collaborated with the program to offer discounted fitness programs and gym memberships. Local churches have offered opportunities for volunteerism on the part of their members. Consulting psychiatrists, psychologists and mediators, dentists and primary care physicians have worked with staff and clients helping to resolve medical, dental, conflict and psychological/behavioral issues. Numerous community specialists have collaborated with program staff by offering a huge variety of trainings to families, aimed at their overall wellness.

Outreach

MCS identifies caregivers in the community in several ways. An MCS brochure listing available services is given to all families. Among those listed are the Parent Networking Groups (including PAG). Along with this brochure, several of the Parent Networking Groups have their own brochure that describes in detail the goals and activities of each group. MCS Service Navigators and DDS Service Coordinators are aware of the PAG and other groups and often refer families to the program whom they feel will benefit from such a group. The MCS Website is available to browse. It includes the core services as well as PAG and Parent Networking Group trainings and activities. Finally, the families themselves are active in bringing other families whom they think will benefit from PAG.

Diversity

Diversity is one of MCS's greatest strengths and a distinguishing feature in our 30 year history of supporting families from different cultures. Cultural, racial, ethnic, age and other differences have always been welcomed by MCS and are hallmarks of the organization. Several of the Parent Networking Groups were established to address these needs. Among them are two Latino Groups, a Grandparents Group, an African American Group, a Vietnamese and Russian Group, and two transition groups. Each group focuses on the unique issues and concerns that families face in overseeing the care of their family members with disabilities. Historically, we have assisted families from Puerto Rico, Columbia, Brazil, Russia, Turkey, Vietnam, Somalia, China, El Salvador, Nepal, and the Ukraine among others. MCS offers comprehensive supports for these families including interpretation and translation,

bilingual service navigation, culturally based supports and cultural celebrations. MCS offers linguistic accessibility through the programs own Translation and Interpretation Services. The program endeavors to be proactive, sensitive, responsive and collaborative in the response to all of the families.

Program Evaluation

The Parent Advocacy Group and other Parent Networking Groups are evaluated in several ways. Since they are family driven, the families have traditionally taken an active part in evaluating the advocate, choosing and evaluating the activities and trainings. In addition, there is an annual survey in which the families themselves evaluate and make recommendations for future revisions. The advocate participates in weekly consultations and yearly evaluations with the MCS Director of Family Supports.

Lessons Learned

Among the lessons learned over the years are the following: PAG, being a group of single elders with declining health issues, have different needs and interests than younger members of other Parent Networking Groups. Their main concern is maintaining the health that will allow them to care for or oversee the care of their sons and daughters with disabilities as long as possible. Trainings are mainly health related or deal with futures planning such as guardianship, wills, and trusts. Meetings need to be held in good weather only, being sensitive to difficulties involved with winter driving. Planning sessions are held at the beginning of each fiscal year to choose the trainings that will best benefit the members.

Members also enjoy some time for socializing and support and do not need for all activities be "planned." They are friends, sounding boards, mentors and challengers to each other and they value these relationships immensely. The need for advocacy on behalf of families never stops. Each new administration/leadership brings the need to get out there and make known the needs of the families.

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SAGE Caregiver Program

SAGE—Services and Advocacy for GLBT Elders
New York, New York



The SAGE Caregiver Program is the only program in the country specifically designed to meet the complete care and support needs of non-traditional GLBT caregivers who are often marginalized

from mainstream services and supports.

Background & History

Incorporated in 1978, Services and Advocacy for GLBT Elders (SAGE) is the country's largest and oldest organization dedicated to improving the lives of lesbian, gay, bisexual and transgender (LGBT) older adults. The mission of SAGE is to lead in addressing issues related to LGBT aging. In partnership with constituents and allies, SAGE works to achieve a high quality of life for LGBT older adults, supports and advocates for their rights, fosters a greater understanding of aging in all communities, and promotes positive images of LGBT life in later years. SAGE fulfills this mission by providing direct and supportive social services, social and recreational activities and community building programs throughout New York City, and education, technical assistance and advocacy programs both locally and nationally.

SAGE's Caregiving Program evolved from "on the ground" experiences of SAGE's Social Services and Community Services staff who identified two significant problems facing LGBT caregivers: 1) caregivers, in general, do not avail themselves of the support available to make their responsibilities more manageable; and 2) LGBT caregivers, in particular, often do not find a supportive environment in mainstream organizations. Additionally, LGBT older adults are twice as likely to live alone and four times less likely to have traditional familial supports (e.g., partners and children) to care for them, thus relying on "families of choice" (e.g., friends, neighbors, ex-partners) to care for them. In recognition of these factors, SAGE created its Caregiving Program in 2004. Since that time, SAGE has continued to respond to the evolving needs of LGBT caregivers by incorporating life-planning services into its supportive caregiving menu to assist caregivers in planning for their own aging futures.

Program Goals

The goal of SAGE's Caregiving Program is to improve the overall quality of life of LGBT caregivers and LGBT older adults through the combination of therapeutic supports, case management and educational programs. Given the nature of caregiving as well as the local and national components of SAGE's Caregiving Program, accomplishment of the Caregiving Program's goal must be measured by degrees. SAGE has numerous stories of individual caregivers who have seen not only an improvement in their overall quality of life but also that of their care recipient. Since its inception SAGE's Caregiving Program has served over 1,000 LGBT caregivers through direct services and thousands more through outreach and educational programming. Despite these impressive statistics, an even larger number of marginalized and isolated caregivers are in need of culturally competent LGBT caregiving services.

Program Description

The SAGE Caregiving Program is the only program of its kind and scale that focuses on supporting LGBT caregivers. SAGE's program provides a comprehensive set of services and programs for any person who is caring for a LGBT older adult or an LGBT person caring for someone. Caregivers in the program can access one-on-one and peer support and assistance from individual counseling and weekly support groups. Additionally, financial assistance is provided to both caregivers and care recipients through benefits and entitlement screenings, home health aide respite services and supplemental assistance to improve the quality of life for both caregivers and care recipients by alleviating short-term financial hardships (e.g., medical co-pays, groceries, rent arrears and transportation costs). Caregivers can also receive assistance in planning for their own aging futures by accessing on-going legal and financial planning clinics as well as educational workshops on aging planning issues (e.g., long-term care). To service the needs of homebound LGBT older adults with limited or no caregiving support, the SAGE Caregiving Program includes a Friendly Visitor Program which matches volunteer caregivers with homebound clients.

SAGE's Caregiving Program also has an on-line LGBT Caregiver Resource Center (launched in March 2011) which is part of the National Resource Center on LGBT Aging (www.lgbtagingcenter.org). The LGBT Caregiver

Resource Center provides LGBT caregivers from across the country the opportunity to access essential articles, guides, resources and multimedia to support them as caregivers and connect them to both local resources in their own community as well as to SAGE's expert staff.

Timeline

The initial planning and implementation phase of the SAGE Caregiving Program took approximately 1 year. The first significant milestone for the program was to create the fundamental structure of the program and submit a proposal to the New York City Department for the Aging (DFTA). The structure of the program was designed by Social Services staff in collaboration with a consultant. Program design drew upon staff experience as well as constituent input. This first phase took approximately 6 months. Once the contract was awarded, SAGE undertook hiring of caregiving staff as well as the process of developing concrete programming and services to be offered at the program launch. The period from contract award to the launch of the program was an additional 6 months.

Financial Issues

The program initially launched with a generous grant from the DFTA that provided approximately \$330,000 per year in support of the program. Over the course of the program's history and growth, the funding required for the program is currently at \$600,000 annually (this is based on \$390,000 DFTA and \$220,000 SAGECAP). This growth was accomplished through on-going support from DFTA as well as local and national foundation support and individual donors. Currently, approximately 60% of the SAGE Caregiver Program is funded through DFTA. The remaining 40% is from other governmental funding, private and corporate foundations and individual donors. For the most part, state and city budget cuts during the on-going financial crisis have not overly impacted the SAGE Caregiver Program. During the on-set of the financial crisis of 2008/2009, SAGE's funding from DFTA was cut for that contract year. To fill this funding gap, SAGE was able to secure one-time funding from several private foundations to ensure the continuation of SAGE's comprehensive services.

Staffing

SAGE's Caregiving Program is supervised on a daily

basis by a Master's of Social Work Director of Social Services. The Director of Social Services reports to the Senior Director of Programs who is responsible for the overall implementation of all SAGE services and programs. Within the Caregiving Program, one Program Manager oversees the Friendly Visiting Program while another manages SAGE's new SAGECAP program. The Director of Social Services supervises both of these Program Managers.

Initially, SAGE's Caregiving Program was staffed by a Project Coordinator, three Masters of Social Work Social Workers, a Director of Volunteers and a Bachelor's of Social Work Administrative Assistant. As the program has grown, the Caregiving Program staff has also expanded. During 2011, SAGE's Caregiving Program was overseen or implemented by eight staff members. Overall supervision and management of the Caregiving Program is done by SAGE's Senior Director of Programs and the Director of Social Services. Direct services are provided by 4.5 Social Workers while administrative and reporting activities are handled by an Intake Coordinator/Data Analyst.

Partners

While the SAGE Caregiving Program is a program solely of SAGE, the program has an extensive network of community collaborations across New York City including area caregiving agencies, senior centers, case management agencies, faith-based organizations, legal service providers, and other community-based organizations. SAGE and its community collaborators share clients, provide mutual referrals and collaborate on support groups and other services.

Outreach

SAGE utilizes a variety of outreach methods to reach and engage caregivers both throughout New York City and across the country. SAGE's marketing and communication efforts effectively utilize both print (e.g., monthly calendars, SAGEMatters (our tri-annual magazine) and on-line (e.g., website, e-blasts, Facebook, Twitter) media. Additionally, SAGE staff members do extensive community outreach in the form of presentations, trainings and workshops locally and nationally at conferences. Lastly, SAGE's outreach efforts are aided by word of mouth by our clients. Word of mouth is particularly important in our outreach efforts given that many LGBT caregivers and LGBT older adults

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are resistant to reaching out to service providers for fear of discrimination.

Diversity

SAGE's Caregiving Program serves caregivers and care recipients who represent the full diversity of New York City including: race, ethnicity, class, religion, sexual orientation, gender identity and age. SAGE leverages our referral network, grassroots efforts (neighborhood-based outreach, word of mouth, faith based-communities), as well as social media and comprehensive communication and outreach efforts to reach diverse populations. Particular emphasis is placed on targeting extremely isolated LGBT older adults and their caregivers in low-income people of color communities, HIV-affected populations and the transgender population.

Challenges & Barriers

Many LGBT caregivers do not self-identify as caregivers; they simply describe what they are doing for a loved one as "the right thing to do." This lack of self-identification can be a significant barrier in engaging caregivers in supportive services that focus on their own health and well-being. Education is a key strategy in overcoming this challenge. By incorporating discussions of caregiving in its many forms and permutations throughout SAGE programming, staff is able to foster an understanding of and respect for caregiving within the LGBT community. Additionally, SAGE works to redefine the term caregiver to stress that caregiving takes all forms (e.g., from daily caregiving to long-distance phone caregiving) which bring their own stressors and challenges. Once a caregiver has embraced the nature of their role, another challenge encountered is getting caregivers to focus on their own health and well-being.

Many caregivers reach out to SAGE when a crisis has occurred with their care recipient and when the crisis has been dealt with, believe they can handle the situation and don't need further assistance or support. SAGE emphasizes peer-to-peer interaction to overcome this perception. In our experience, the best way to get caregivers to focus on their own needs and well-being is to foster communication between caregivers through on-going support groups and short-term educational programming and peer-focused special events. A final challenge for caregivers in accessing supportive services is time. Caregivers, especially those who are

still in the workforce, have very limited free time to access caregiver-centered services. It is imperative that programming and services be offered on a flexible schedule that ensures equal access to services through day and evening hours as well as weekday and weekend programming.

Program Evaluation

The SAGE Caregiving Program has not been formally evaluated. Currently, DFTA measures program effectiveness by projected annual service units. Both DFTA and SAGE are in the process of moving towards a system of process and outcome evaluation which will be implemented in the next couple of years.

Lessons Learned

- One size does not fit all. Programming and services must be flexible and adaptable to caregiver need. Approaching services as a menu of options rather than a strict intervention will not only engage more caregivers (especially those initially resistant to supportive therapeutic services) but also allow staff to adapt service plans to meet the distinct needs of each individual.
- Listen, Listen, Listen. Incorporate consistent feedback mechanisms into program design to ensure that services are meeting caregiver's needs as well as to identify growing trends so that the program can proactively adapt or create services in real time.
- Give caregivers time. Caregiving can be very stressful experiences for caregivers and it may take caregivers time to prioritize their needs and access services. Keep in touch with caregivers who defer services for themselves. Begin to build a relationship of trust with the caregiver. In all likelihood, they will need assistance at some point in the future and will be more likely to seek services for themselves if staff has made the effort to create a foundation of trust.

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Caring for Caregivers

The Pro Bono Counseling Project
Baltimore, Maryland

THE • PRO • BONO COUNSELING PROJECT

Caring for Caregivers links low-income, uninsured, and under-insured caregivers with licensed mental health professionals who donate their time and skills for families of persons with cancer, Alzheimer's disease, and multiple sclerosis, disabled veterans, among others.

Background & History

The Pro Bono Counseling Project assures that uninsured, under-insured, low-income families and individuals requesting mental health care are linked with volunteer licensed mental health professionals and other necessary supportive services. The Pro Bono Counseling Project is a 501(c)(3) non-profit organization that was formed by the professional mental health societies in 1991 to support the volunteer efforts of their members, to equitably distribute those cases that could not be served by any other means, and to collect and report data. During the past 20 years, the Pro Bono Counseling Project has provided access to mental health care for more than 17,000 families, individuals and groups throughout the state of Maryland who are uninsured, under-insured and have low incomes. More than 1,500 licensed mental health professionals have provided in excess of 68,000 hours of therapy, essentially donating \$6,225,000 of professional health care. In 2010 alone, clinical social workers, psychologists, marriage and family therapists, professional counselors, psychiatrists and nurse psychotherapists donated 6,173 hours to 928 clients.

Program Goals

For 120 years, the Pro Bono Counseling Project has linked low-income, uninsured caregivers with therapists, but only recently became aware of their unique needs sufficient to create a program, *Caring for Caregivers*. The goal of the *Caring for Caregivers* program is to assist all caregivers who have limited resources to have access to therapy and the support that they need to do their job effectively and to also live full lives.

Program Description

Caring for Caregivers is conducted in three steps. First, outreach is organized and conducted by the Program Director who visits and sends brochures and information packets to hospitals, hospice, specific programs that respond to those diagnosed with life-long and terminal illness, houses of worship, senior groups and others to inform and train staff and community members about the free counseling offered to caregivers. The next step, the clinical services, including intakes, information and referral are conducted and documented by the Pro Bono Counseling Project clinical staff members who respond to requests for care within one business day and discretely link caregivers within 7-10 days with a licensed and insured clinician who has offered to take at least one case annually.

A third essential step includes therapist recruitment. Not only is it necessary for the Pro Bono Counseling Project to maintain an active roster of therapists who are within 20 minutes distance of clients, but also to have therapists who have training and skill in working with the needs of caregivers. By offering free workshops in key subject areas that provide continuing education credits, the Pro Bono Counseling Project is assured that participating therapists are well-trained and rewarded for their altruism. For example, in March 2009, *Caring for Caregivers* provided a three hour workshop for 88 therapists on the subject of assisting caregivers of loved ones with Alzheimer's disease. In October 2009, a two hour workshop was offered in partnership with the Multiple Sclerosis Society on the same subject.

Timeline

A student intern's research project showed staff that 45% of the program's cancer patients were meeting with their therapists with their caregivers. As a result, staff realized that they needed to gather more data differently, recruit and train therapists in the subject area and conduct outreach to different resources. The program applied for and received funding within six months of this discovery and added staff time to expand the work that was already in place.

Financial Issues

The program started with a \$25,000 grant from a local family foundation. The actual budget is about \$75,000. The program returns to local family foundations for funding. The program is not aware of state or federal funds that would fund this work.

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Staffing

Over all management is the responsibility of the Executive Director. The Clinical Director works with clients and therapists. The Program Manager reaches out to agencies and plans the continuing education for therapists. The Executive Director works with the Office Manager to recruit therapists and compile reports.

Partners

The primary partners are the therapists who provide the counseling. Additionally, the agencies, hospitals and hospices, and Houses of Worship that refer caregivers are also key partners. They have not changed, just expanded and grew.

Outreach

The Program Manager contacts Houses of Worship, hospitals and hospices, Departments of Aging and respite programs and sends them cards that they may use for referrals.

Diversity

The program has always worked with a diverse population, because staff outreach to uninsured families and individuals who have low incomes. The individuals are referred from a myriad of sources.

Program Evaluation

The program is in the first stages of conducting an evaluation that is being overseen by the Johns Hopkins University School of Public Health. The program is gathering baseline data and conducting one-month interviews of these clients after they are linked with a therapist. The program will then conduct interviews at three and six-months with these same clients until it has a sample of at least 200 with complete data. The program will be gathering this data until 2012.

Lessons Learned

It is important to identify the client population—some caregivers are more sympathetic than others when it comes to funding; and some caregivers are easier to assist than others.

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Caregivers Community Network

James Madison University
Harrisonburg, Virginia



In conjunction with a university service learning course, Caregivers Community Network teaches students about caregiving and provides respite and companion care services to families caring for frail or disabled older adults in rural Virginia.

Background & History

Two faculty members at James Madison University (JMU) researched the unmet needs of family caregivers through a survey. Caregivers Community Network was founded in 2001 as an Alzheimer's Demonstration Model program by JMU in partnership with the Central and Western Virginia Alzheimer's Association and was designed to supplement existing services without duplication. The program was supported for seven years by grants from the Virginia Department for Aging.

Program Goals

The goal of CNN is to provide support services to caregivers of frail elders and people with dementia, preserving an independent lifestyle for both the elder and the caregiver. The program has accomplished this goal for their client families. CNN knows it has accomplished its goal because caregivers are surveyed twice a year in addition to the students and volunteers checking in with caregivers by phone on a regular basis.

Program Description

Caregivers Community Network (CCN) is a unique campus – community partnership program that offers carefully coordinated support for families who live with and care for frail elders. CCN is a lifeline of support for these families who are trying to keep their loved one at home for as long as possible. It is the only program of its kind in our community that serves this purpose on a sliding fee scale.

Specific client services include in-home respite and companion care provided by students and community volunteers, follow up phone calls and support between visits, errand running, links to other community services, access to a toll-free help line, and educational opportunities. Caregivers and any older adult family

members who have difficulty performing activities of daily living or who suffer from memory loss are eligible to participate in the program. In 2010 students and community volunteers provided 6,120 hours of respite care or other services to 68 families. Since CCN began in 2001, more than 785 students and volunteers have helped 179 families by providing 22,232 hours of respite care (as of 6/30/09).

The CCN staff recruits and trains community volunteers and students from JMU courses within health and human service academic programs to provide respite services. Staff members visit and assess each family, carefully match family needs with the skills and availability of volunteers providing care, and provide follow-up phone support. This service learning model creates intergenerational relationships while providing “hands on” learning opportunities and establishing long-term community connections for students in human service fields.

Timeline

It took two years to research the needs of caregivers in the community and secure funding to pilot caregiver respite services.

Financial Issues

Initial funding from the VDA was \$100,000. Currently, CCN is funded through United Way, Client Fees, JMU and grants. The program lost state support a couple years ago due to budget cuts. Since that time, it has had to confine the services to the Rockingham County/Harrisonburg area only. The program has trimmed expenses, and reduced staff. The current annual operating budget is approximately \$46,600 with another \$20,000 proffered by JMU in-kind.

Staffing

CCN has a fulltime Program Director. The executive director is a faculty member who works with the program on an in-kind basis. A volunteer Advisory Committee provides support. As a program of JMU Institute for Innovation in Health and Human Services, oversight of fiscal and personnel policies are determined by the university. In the early years, CCN employed as many as four part time people in fairly specialized roles of program development, marketing, fundraising, and forging relationships with community partners. The

organization has always utilized faculty release time and graduate assistants as well. CCN has streamlined its paid staff to one fulltime program director with a broad set of responsibilities. This effectively sustains the program because after ten years, it is well established and requires less marketing and public relations. It also limits potential growth and innovation because the activities of training students and providing and evaluating services for 40-50 families are a full time job.

Partners

CCN is a grant-funded outreach program of the Institute for Innovation in Health and Human Services (<http://www.iihhs.jmu.edu/>) at JMU. Consistently ranked as the top Master’s level state university in the south by *U.S. News & World Report*, JMU is among 546 colleges and universities named to the 2008 President’s Higher Education Community Service Honor Roll for its commitment to Community Service-Learning. The key partnership is with the Department of Nursing, which provides fiscal oversight, grant and report-writing assistance, and assistance with the academic course in which students enroll for service learning in the program.

Other important partners include the United Way, the Area Agency on Aging, the Alzheimer’s Association and Rockingham Memorial Hospital, and Social Services. These community program partners were chosen for their role in sustaining, furthering or facilitating CCN’s reach in the community. While the partners have remained fairly consistent, their level of involvement has changed over time. United Way increased its level of funding when state funding was lost. Alzheimer’s Association involvement decreased when they initiated their own “Community Connections” program. Rockingham Memorial Hospital stepped up last year to put their resources behind coordinating the Caregivers Getaway Day event previously overseen by CCN when CCN needed to reduce staffing.

Outreach

The program staff and volunteers do several presentations and participate in health fairs each year. CCN also maintains regular contact with referring agencies.

Diversity

The majority of client families served by CCN are rural caregivers with limited financial resources. Seventy

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one percent of clients served by CCN fall into the “No Charge” level of the federal poverty sliding fee scale from the Virginia Department for the Aging. These clients earn no more than \$10,830 per family member per year and they are unable to afford to pay for services. CCN is the only source of in-home companion care for families who cannot afford to pay for services. During 2011, CCN continually has a steady wait list and receives inquiries from five to six families per month who cannot pay and who must wait at least a semester to receive services.

Challenges & Barriers

Enlisting enough community volunteers during the summer months to provide consistent service has been an ongoing challenge. During spring and fall semesters, there are more than enough volunteers because of the student population at JMU. Establishing predictable year-to-year funding is our other major challenge.

Program Evaluation

CCN gathers data from caregivers, frail older adults who are not cognitively impaired, and students to systematically assess how the program has met the needs of each. CCN collects and analyzes data that provide meaningful and practical information to guide program services.

Lessons Learned

One of the lessons learned was the importance of building community awareness and support. This required systematic and intensive work in the early years, supported in part by a Robert Wood Johnson Faith in Action Grant. CCN was able to extend its services by taking the lead in organizing a local Caregiver Coalition of agencies that serve caregivers. Members of this coalition were able to develop creative educational resources, jointly provide a Caregiver Getaway Day as well as a conference for caregivers annually. A second lesson learned was the importance of having a strong program director who is passionate about the vision and mission of the program. Another key consideration is the strength of the campus–agency partnership.

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DARTS Workplace Eldercare Seminars

DARTS
Minneapolis, Minnesota



DARTS supports caregivers in the workplace with education and resources, brings confidence to the caregiver, payback to the employer, and a needed spotlight on aging and caregiving.

Background & History

In 1974, DARTS began providing area seniors with community connections and transportation services. DARTS is a respected 501(c)(3) nonprofit organization that provides valuable services and resources to older adults and people with disabilities, their caregivers, and the communities in which they live, work, and volunteer. DARTS now impacts nearly 8,000 individuals annually and is a statewide resource to other nonprofit organizations, government agencies, and businesses involved in, or concerned about, aging and caregiving issues. As one of the first Twin Cities organizations to recognize the need for caregiver support services and education, DARTS launched efforts in the late 1980s that have evolved into a comprehensive menu of caregiver services, including a website, respite support, coaching and counseling, support groups, and a resource library.

In responding to the unprecedented age wave, DARTS knew that working caregivers and the aging of America are inextricably linked. In 2001 DARTS approached local businesses to publicize a Caregiver Forum they were presenting in their area. Several businesses asked if DARTS could do an on-site lunchtime seminar on the issues. DARTS' targeted telephone contacts, follow-up emails, and in-person visits resulted in significant interest in workplace eldercare education from larger employers. This direct expression of need, along with broader calls for organizations like DARTS to be more engaged at the worksite, led them to begin building the Workplace Eldercare Seminars (WES) program.

Program Goals

The Workplace Eldercare Seminar (WES) program has two main goals. The first is to build working caregivers' resourcefulness, competence, and confidence. The second is to assist employers in providing work-life balance for working caregivers. The effectiveness of WES is evident in the caregiver and employer evaluation survey data that DARTS compiled and in the "repeat business" the program experiences with employers and employees.

Program Description

DARTS' eldercare seminars at workplaces connect caregivers of elders with resources to make the journey easier. Often a brown-bag session over the noon hour, these seminars address a major work-life balance issue for employer and working caregiver alike. Topics include:

Strategies for Caregiving

- Family Caregiving Strategies—Learn about resources and strategies that can help maintain everyone's dignity and connectedness.
- Critical Conversations—Good communication strategies help families build cooperation, develop work plans, and make decisions.
- Cooperative Caregiving—Scout this territory of common conflicts, possible resolutions, and criteria for family satisfaction.

Critical Issues in Aging

- Housing Decisions—Housing decisions take on new dimensions as people age. Learn the pros, cons, and finances of staying at home, independent senior housing, home services, assisted living, and nursing homes.
- Financial and Legal Issues—Power of attorney, specialized insurance, financial needs, and other tough issues are best explored sooner than later.
- Dementia and Memory Loss—Many elders remain alert, yet most fear the loss of memory and reason above all else. Their families do, too. Learn about memory loss symptoms and complexities.
- Community Resources —Needs change continually as we age. Whether you are near or far from your elder, community resources can make life better. Explore service availability, costs, and benefits.

DARTS has partnered with well over 50 employers to provide education and support to employed caregivers. In addition to the seminars, a number of collateral resources are made available to employers and caregivers. These include Working Caregivers: A Business Case, Workplace Flexibility and FMLA, a caregiver identification poster, a support group guide, and mini white papers on distance caregiving, LGBT caregiving, and setting limits for resilient caregiving. Behind the seminars is a suite of DARTS caregiver services that seminar attendees can access, including referral to other providers.

Timeline

WES was developed within an environment of community education and services for caregivers and complementary direct services for care receivers. This backdrop of comprehensive resources sets WES apart from standalone education programs. It also allowed for a gradual development of the WES platform. In 2001, the program tested its first workplace education format. In 2003, funding and staff time were dedicated specifically to WES which allowed for seminar refinement for business audiences, initial corporate outreach, and stand-up presentation time. In subsequent years, outreach efforts increased, different media were explored, curricula were adjusted based on customer feedback, and unique, topic-sensitive materials were developed.

Financial Issues

The programs first dedicated funding for WES in 2003 was approximately \$75,000 from the local Area Agency on Aging (Title III-E Older Americans Act dollars) and the Greater Twin Cities United Way. In 2011, this amount is approximately \$30,000. The program generates revenue through employer purchase fees, but the service would not be self-sustaining without additional program and general operating support coming from DARTS' fundraising efforts. The staff members producing WES have many other roles at DARTS, and the program has been able to maintain their WES involvement despite funding challenges up until this year. Overall agency resource constraints have led the program to curtail most targeted corporate outreach strategies for the second half of 2011. The program will continue to provide seminars as requested, but are not able to continue to actively foster the

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business-to-business relationships necessary to advance the program at this time. The business customers have suffered in the recessionary economic environment as well, making education products less of a priority in the last few years. The hope is that WES will re-emerge in a new and even stronger form in 2012, in a more vibrant and motivated business climate.

Staffing

WES is one of many caregiver and older adult services at DARTS and is managed within the overall organizational structure. Four DARTS professionals were the key staff of WES at the outset, comprising 1.35 FTE. The same staff is involved now, but all at reduced levels totaling approximately .75 FTE. The Service Coordinator/Educator provides content expertise, presents the seminars, and responds to attendee follow-up. The Manager of Education/Training develops the seminars, manages customer service and program evaluation, assists with seminar marketing, and leads program development. The Director of Communications provides marketing expertise and leadership on corporate partnerships and program strategy. The Chief Operating Officer links WES with agency priorities, oversees all caregiver services, and is the liaison with funders and external partners. This level of staffing resulted in 29 seminars to 495 caregivers in 2010, a low year due to the economic pressures experienced by our organization and our customers.

Partners

The WES program was independently conceived and developed, with financial support from the local Area Agency on Aging and the Greater Twin Cities United Way. Over the years, the program has entered into a number of seminar delivery partnerships with corporations, academic institutions, and the local public television station.

Outreach

The program has done several outreach efforts that include the following:

- Made targeted calls and mailings to potential business customers and have pursued relevant DARTS connections, such as board of directors' representation, corporate volunteering connections, and corporate donors or sponsors.

- Advertised in targeted publications.
- The WES program is represented in all broad agency communication tools.
- Created new pre-sale collateral yearly, based on customer feedback and program goals.
- Encouraged customers to book multiple seminars and offer incentives for referrals.
- Once a company has hosted WES, the staff continues to build caregiver awareness and support within their environment through targeted information and ideas for employers to recognize working caregivers.

Diversity

In proportion, more male caregivers participate in WES than in our other caregiver services. The vast majority of attendees are under age 60. Our materials are in English, which suits most workplace environments in the Twin Cities. Each WES attendee receives a list of culturally appropriate services for caregivers and they learn about DARTS' caregiver website, which includes information in Spanish and a section culturally appropriate for Hmong families. To broaden potential reach, DARTS offered free electronic documents of our seminars to several culturally specific agencies in 2008, encouraging them to customize the materials to meet the needs of their constituents.

Challenges and Barriers

WES has difficulty reaching retailers and manufacturers – employers of part-time and shift workers – and those who insist on usability at all divisions located around the country. Barriers to employee participation sometimes include travel schedules, field work, fear of management bias against eldercare activities, and work priorities. Various WES clients have overcome barriers through double-scheduling at different times of day, closed circuit media access across the state, and videotaping for on-demand availability via their intranets.

Effective marketing on a shoestring has been a challenge. WES developed a business case and other collateral for use with investment-oriented decision makers, revised the “packaging” of seminars for multiple sales, and engaged an HR consultant to research and develop a “sales map” for our program based on online surveys and focus groups. This has led to efforts

that will stimulate peer-to-peer buzz about DARTS' offerings, such as beginning to build a presence on LinkedIn.

Program Evaluation

WES uses three evaluative methods:

- End-of-seminar evaluations gather immediate attendee feedback on content, skill enhancement, group process, and demographics.
- Mail-back evaluations of participant materials elicit feedback on print materials and the seminar itself.
- Employer evaluations solicit before- and after-seminar observations of employee interest and evidence of culture/environment changes.

In 2010, 91% of attendees said that WES will help them provide care longer or much longer, 96% reported an improved ability to provide care, and 96% said WES helped them cope somewhat or much better.

Lessons Learned

The program had expected that mailings, advertisements, and cold calls would be more efficient and effective in selling to employers. The staff hired a sales consultant for telemarketing, but found that unsuccessful. A lesson learned is that “buyers listen to peers, not pitches,” which indicated a need for a different marketing and sales philosophy.

A useful element to build into a newly developing program would be employer measures of increased productivity. The program staff approached a few employers about this, but they thought such measures would be expensive to develop and maintain. They would, however, significantly aid a return on investment sales pitch.

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Dementia Skills Training for the Home Caregiver

The Copper Ridge Institute
Sykesville, Maryland



Dementia Skills Training for the Home Caregiver brings practical training, problem solving skills and support to caregivers where they are, at home, via the Internet or on a DVD.

Background & History

The Copper Ridge Institute is a nonprofit organization that conducts research on, and education about, the care of people with Alzheimer's disease and other memory-impairing disorders. The Institute, affiliated with The Johns Hopkins University School of Medicine, has developed a model of care that is recognized nationally and internationally and has hosted caregiving experts and researchers from 12 countries. The underlying philosophy of the Copper Ridge Model of Care® is that the residual cognitive and functional capabilities of the person with dementia should be maximized with a proactive approach that adapts to the person's changing abilities. The multidisciplinary approach to care focuses on providing the highest possible quality of life and support for both the patient and caregiver. For the past fifteen years The Copper Ridge Institute has taken a leadership role in improving Alzheimer's care. Fourteen years of clinical work, research and collaboration has enabled The Copper Ridge Institute to establish a program of care and treatment that offers benchmark standards of care as we all wait for and work towards a cure.

Program Goals

The Dementia Care Education program—available on a DVD and on-line—presents educational information that helps family caregivers to provide the best care possible by supporting them with the most up to date information and scientific findings.

Program Description

The Dementia Care Education program for the Home Caregiver is an educational tool whose purpose is not only to impart information about Alzheimer's disease

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but to teach the home caregiver successfully researched skills and best practices and to develop the care giver's ability to problem solve, a vital component in caring for a person with Alzheimer's disease.

This hour long program engages the caregiver as they meet our "video" family that is, just like them; facing Alzheimer's disease with a loved one. So during the experiences of visiting a doctor, learning about Alzheimer's disease and its progression, involving an adult child, interacting with grandchildren, seeing the struggles of life's daily activities; the home caregiver is not alone. They are not being lectured to, they are not in a stressful social situation, they are open to listen and learn because they are journeying with another family, struggling as they struggle.

The challenges that are universal to the Alzheimer's caregiver are addressed in specific segments of the program, which can be revisited as many times as needed for clarification and increased understanding. Whether the caregiver is learning on the Internet or through the DVD, access is not limited to a specific time or order. The program addresses challenges with bathing and dressing, eating, toileting, sleeping, wandering, hoarding, aggression, hallucinations and delusions, delirium, medication, and recreational activities. Real family members are experiencing the problems also facing the viewer and both families are being helped. There is no embarrassment, no need for denial, just straight forward presentation of the disease and coping strategies. Strategies that have been developed from fifteen years of clinical work, research and practice at the Copper Ridge Institute are presented in the program.

The educational program is designed to teach the home caregiver the "5D Process" in addition to the previously described skills education. The 5 D process has the goal of equipping the care giver with the ability to meet the challenges particular to the individual being cared for. They are:

- **Describe** the behavior/challenge/symptom.
- **Decode**—Why does your loved one have this behavior/challenge/symptom? Is it because of their thinking and memory problem? Is it because of a physical or medical problem such as needing to go to the bathroom? Is it psychiatric problem such as depression? Is it because of the environment, is the room too cold or is there too much noise? Is it

because of the approach of the caregiver? We don't want to argue, lecture or rush.

- **Devise** a plan, looking at the behavior/challenge/symptom and all the possible causes. What can be done to change the behavior of your loved one?
- **Do it**—Try the different solutions that you come up with, one at a time.
- **Determine** if the solution works. If it does, communicate it with everyone caring for your loved one. If it doesn't work, please don't give up, try another approach.

Staff strongly believes that this part of our program empowers the caregiver to not only understand what Alzheimer's disease is, learn techniques of care, but also feel they can be in charge of their caregiving. Feeling in control, although times will be difficult and challenging, will help to diminish stress and the feeling of helplessness. The program also presents the need for caregiver support from friends and family. Caring for one's self is a challenge for the caregiver. Our program directs the caregiver to pursue caregiver wellness, an admonition they need to hear very often.

The goals for the caregiver and this program are very high. Education, skills training, and proactive problem solving and caregiver wellness are not readily achieved. However, the program is a solid beginning which we know will bring the caregiver support in the great challenge they face every day.

The program has been in existence since May, 2008. Since then there have been 205,000 visits to the caregiver program on The Copper Ridge's alzcast web site. Approximately 1,500 DVDs have been distributed. The home caregiver training program is designed to reach the broad spectrum of caregivers. It is designed to reach a universal audience and not be limited to certain types of home caregivers.

Financial Issues

The total budget for the program was \$150,000 dollars. A total of \$75,000 was given by the Middendorf Foundation of Baltimore. The Copper Ridge raised a matching \$75,000 from private donors and other charitable foundations.

Staffing

After production was complete, there is no staff needed to reach the individual family members. As the country and the world deals with the epidemic numbers that are affected and will be affected by Alzheimer's disease, technology is the only answer to make the numbers work.

Fifteen years of social and clinical data and research by geriatricians, Hopkins neuro-psychiatrists, nurses, geriatric nursing assistants, recreation therapists, other professionals and family members are the substance of this program. Institute staff then developed the learning areas, wrote the script, and worked with the actors and technology production staff. Once the modules were completed the time and energy of all these contributors are no longer needed, but their expertise can be shared with multiple thousands of family caregivers.

Partners

The Copper Ridge Institute has been affiliated with the Johns Hopkins School of Medicine for the last fifteen years. Our Copper Ridge Model of Care is a treatment and care approach to Alzheimer's disease and other memory impairing illnesses which has been developed during this collaboration. We also have had a strong relationship with Astute Technology. Under the leadership of their CEO, Dr. Jon Merrill we have been guided and introduced to the most effective and innovative technological strategies to reach our targeted audiences.

Staff brings the program to the caregiver's home. Whether on the web or by DVD, the education and training are available 24/7. In addition to providing information, staff seek to teach a skill; hands on, real life issues with practical solutions, shown with real people. Staff aspire to teach the home caregiver the 5 D tool, helping the caregiver to "take charge" of his or her caregiving. And the program never goes away; the program can be referenced as many times as needed.

Program Evaluation

When the caregiver is finished viewing the program they have an option of filling out a survey. Traditionally, staff has found that most caregivers who are using an online tool don't take the time to respond to surveys. In 2010, completed surveys were received from 39 people; 97% of the respondents found the program very helpful.

Also measured is the ability to reach our target group, the home caregiver, by the number of people who have visited the site. To date over 205,000 caregivers have reached our program through the web. The program also has received positive comments from organizations across the globe. Australia's Alzheimer's Association named our site as "website of the week," Ageless Design website recommended us to their international audience; and the University of South Florida recognized the value of the caregiver outreach.

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Native Caring: A Conference to Learn, Connect and Share

Community Action Program of East Central Oregon
Pendleton, Oregon

The Native Caring training conference provides caregiver workshops and activities integrally tied to spiritual, physical, mental and social harmony, which are key elements of the Native value system of care.

Background & History

The Community Action Program of East Central Oregon (CAPECO) is a 501(c)(3) non-profit organization serving four rural counties in Eastern Oregon.

CAPECO is comprised of four departments including the Area Agency on Aging (AAA) which administers the programs and services of the Older American Act, including the Family Caregiver Support services. The CAPECO AAA director works collaboratively with the local tribe and is an active member of the statewide Native Caring Committee.

In 2004, while attending an Older Americans Act Title VI meeting in Seattle, WA, several staff from the various tribes of Oregon and the DHS State Unit on Aging met and proposed coming together to discuss common concerns and obstacles they faced in delivering quality services within their own tribes for family caregivers. The common theme was the lack of resources to provide meaningful and culturally-relevant training for caregivers within their own service areas. It was at this time that the group formed the Native Caring Committee with the goal of pooling their resources in order to provide a statewide training conference that was not only geared to the Native American culture, but also would provide a time of getting away from their caregiving duties to refresh their body, mind, and spirit.

Program Goals

The goals of the Native Caring conference are to:

- Provide educational workshops in a cultural environment tailored to the needs of the Native American population.
- Provide opportunity to honor traditions such as drumming, prayer in native tongue, native foods, dancing and other relevant activities.
- Provide an opportunity for caregivers to have a break from their caregiving responsibilities.

- Provide a platform where caregivers can network and share common concerns/issues related to their role as caregivers.

- Provide a forum for increased collaboration and coordination of tribal, federal and state programs.

The Native Caring Committee has accomplished its goals through evaluations conducted at each of the conferences.

Program Description

The Older Americans Act requires Title VI and Title III to coordinate those services that are provided within the Title VI service areas. To address this coordination, Oregon has developed an on-going committee called the Native Caring Committee comprised of the Department of Human Services, State Unit on Aging, representatives of each of the nine tribes and Area Agencies on Aging that are within a tribal area. The yearly conference, *Native Caring: A Conference to Learn, Connect and Share* is the primary focus of this group. In 2011, the seventh *Native Caring* conference was held. In addition, the group functions as an information and idea exchange, sharing of best practices, developing and updating the Oregon Tribal Caregiver Program Standards and providing staff training.

The primary objective of the conference and trainings has been to increase the knowledge of self-care with Native American caregivers and enhance their quality of life along with their loved ones. In keeping with the many cultural values of tribal communities, most elders live with their children, grandchildren, or other members of the extended family. As a result, the daily care of those suffering from chronic diseases and disabilities falls to the family member. Providing support to these caregivers is important.

Workshops cover topics related to:

- Alzheimer's disease and related dementias, diabetes, heart disease, nutrition, depression, healthy aging, Chronic Disease Self-Management
- Caregiver dilemma table game (small group interaction regarding different situations)
- Elder abuse and financial fraud
- Falls prevention
- Preparing to care
- Communicating effectively with healthcare professionals

- Medication management
- End-of-life issues
- Self-care for the caregiver
- Grandparents/relatives raising children
- Addictions
- Physical fitness/exercise and stress management
- Various entertainments and fun activities

Up to 30 vendors also participate and they include information and resources such as: Medicare, Medicaid, Emergency Preparedness, Long Term Care, Cancer Care Resources, Women’s Health, Financial Planning, and other Healthy Aging entities. Each tribe invites their pow wow vendors to sell jewelry, baskets, blankets, native American clothing attire and other cultural items.

Timeline

Planning the event can take between three to 12 months depending on the size of the event and availability of a facility and speakers. The following are steps and time frames for the Native Caring Conference:

1. Secure location—12 months in advance of event
2. Determine Host Tribe—12 months in advance
3. Secure sponsorship commitment from tribes—(dollars set aside in Title VI budgets)
4. Develop budget—9 months in advance
5. Convene committee for initial planning meeting—9-12 months in advance
6. Develop and distribute a Save the Date Flyer—6 months prior to event
7. Meet bi-monthly up to month before event for progress reports
8. Obtain speaker biography, AV needs—3 months prior.
9. Host tribe keeps in constant contact with the Marketing Director of the conference facility
10. Develop final agenda and finalize conference brochure—2 months prior
11. Committee members solicit door prizes and items to be put in tote bags (snacks, pens, tablets, etc)—at any time prior to event
12. Order tote bags (sponsor logos and name of conference printed on bags). This usually can be done

within 6 week prior to event

13. Assign one agency to collect registrations and prepare name tags

14. One month prior to event committee meets to evaluate the entire event and identify any problems. Last minute speaker cancellations may occur and an alternate is obtained. Host tribe meets with tribal council members to determine opening and closing ceremonies

The existing Native Caring Committee has worked together for seven years with little turnover. They are a solid group with passion to make the health of their people a reality. They have positively modeled inclusiveness by partnering with others to better serve their communities. Over the years, it has developed a strong network of professionals who are eager and willing to volunteer their services, most without charge, to provide workshops.

Financial Issues

The conference is primarily funded using Title VI and Title IIIIE funds from the Older American Act. Tribes, who are able to do so, budget for this annual event by setting aside dollars to contribute towards the cost of the conference. In addition to their designated dollar commitment, one or two of the tribes have also paid to bring in a nationally renowned key note speaker. Nearly all of the presenters contribute their time free of charge. If overnight stays are required, the expense, when requested, is covered by the event. Since all of the events are held on a local reservation at their casino and conference facility, planners are able to leverage support from them through reduced meals, waived conference room and AV fees, tribal rates for lodging, folders for the conference brochure, pens, tablets, etc. The host tribe supplies a dinner and breakfast.

The program has established a \$125 registration fee per participant. Most generally this fee is paid by the local tribes. Additionally, the tribes provide transportation to and from the conference and also pay for lodging. Scholarships are available for those who are unable to pay this fee if they reside within the State of Oregon. The program also has up to 40 persons from tribes in parts of Washington, Idaho, Nevada and California who regularly attend.

Committee members have written grants for the conference and to date we have received the MetLife Foundation Award and the Multicultural Health Grant

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through the Oregon Department of Human Services. The Oregon AARP has supplied in-kind speakers, evaluation polling and pedometers for a walking event during the conference. Local Area Agencies on Aging have given money towards scholarships and sponsored morning and afternoon snacks for breaks.

Staffing

The Native Caring Committee is facilitated by the State Unit on Aging and meetings occur six to eight times per year with the Oregon tribes, Area Agencies on Aging, Oregon Commission for Children and Families and AARP. The group is self-managed and sets the agenda for staff trainings and other events throughout the year.

The project operates through the efforts of the established committee, all of whom have expertise in either the delivery of caregiver services or have a professional involvement in the area of caregiving to Native caregivers. It is imperative that one person acts as the lead facilitator whose responsibility it is to call meetings, develop an agenda, assure minutes are taken and distributed, and assign tasks. The project only succeeds through the commitment of all of the partners and their reliability to carry out key assignments.

The number of committee members and their involvement is contingent of the size of a project or training event. Oregon's two day event with over 250 attendees now requires the dedicated involvement of at least 10 committee members who can devote at least eight hours per month in the early planning stages and full commitment at the time of the event. Due to the growth of the project over time the amount of staff time needed has doubled. So has the size of the committee.

Partners

Partners include representatives of the nine tribes of Oregon (elder coordinators and clerical staff); Area Agencies on Aging; Department of Human Services, State Unit on Aging; Commission for Children and Families; and AARP.

Outreach

The Native Caring Conference is publicized through a network of elder coordinators in Oregon, Washington, Idaho, California and Nevada, Tribal newsletter, OlderIndian.org, tribal health clinics, the Administration of Aging Region X, AARP news, the Oregon Department of Human Services State Unit

on Aging Website, various local newspapers, the NW Portland Indian Health, the Area Agencies on Aging, and Department of Human Services Children and Families as well as through word of mouth.

Diversity

Native elders living on reservations or urban areas hold a special place in the Native community. Native elders represent many things including family, culture, traditions and the overall well-being of the community. Elders are closely tied to their children, grandchildren, extended family, caregivers and community programs. By focusing on elders and elder caregivers, a dynamic and holistic picture is painted. This picture is the foundation to the health equity plan that will be guided, directed and developed with the vision and wisdom from the elders for future health care.

The Native Caring Conferences are provided in a cultural environment on or near reservations throughout the State of Oregon. As mentioned, this allows the opportunity to honor traditions such as drumming, prayer in native tongue and native foods. Multi-generations of Native Americans (including school children) have been able to showcase their tribe to participants. Tribal Council leadership opens and closes each conference.

Workshops and activities are carefully tailored to meet the cultural needs of the participants. Presenters are recruited from fields of expertise and those who are familiar with native culture.

Participants are recruited by their respective tribal programs that provide caregiving duties to tribal elders as established by their tribe and those who provide care for grandchildren and disabled individuals.

Challenges & Barriers

One challenge is the financial hardship for representatives to get together in one location due to shortage of funds and distance of travel. To attend a one day meeting, it may take someone out of their office for two days. Meetings are held in a location with the availability of conference calling to enable all to connect.

A second challenge is that caregivers are reluctant to leave the person whom they provide care. Through Title VI funds they are given the opportunity to have a respite care provider for the period that they are away. Those

who have previously attended now know the value of having this time away and look forward to attending the following year. They have also been instrumental in persuading others who are also reluctant to attend.

Program Evaluation

Participants are provided the opportunity to complete an evaluation on each of the workshops and keynote addresses. They are asked to rate not only the content and its usefulness, but also the presenter. Results are compiled and evaluated by the committee and considered for future events. These evaluations have proven the value of the conference to the participants as evidenced by the high degree of satisfaction. During the last two conferences, AARP has conducted an electronic pre- and post-polling evaluation.

Lessons Learned

It is imperative that a single member of the committee is not solely responsible for the major aspects of the project. The program relied on one person in the first three conferences who willingly and very efficiently assumed the responsibility of many major tasks. When this person left the committee due to a change of jobs, the committee had to scramble to gather the information it needed to proceed efficiently. The staff has since compiled a notebook which contains all the necessary information to replicate the conference. Throughout the years the staff has developed a bank of speakers who are willing to present from year to year.

The program has found that having too many sessions running simultaneously was neither beneficial nor well attended. When too many sessions are scheduled at one time, it is hard for participants to choose what they want to attend. Some sessions became overcrowded, while others were sparsely attended. The staff has since planned the first day to be in total general session and the second day with only 4 workshops running simultaneously. There are 8 sessions in the morning and these same sessions are repeated in the afternoon.

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Future Care Planning Services

Lifespan, Al Sigl Center and The Arc of Monroe County
Rochester, New York



Future Care Planning Services (FCPS) mission is to help aging caregivers develop written health, housing, legal, financial and guardianship plans pertaining to the future care of their loved ones with disabilities.

Background & History

By 2000, staff at Lifespan of Greater Rochester Inc., a local non-profit provider of services for older adults and caregivers, had begun noticing that increasing numbers of families were facing crisis situations because caregivers were aging out of their ability to care for their also aging adult children with disabilities. The situation was crystallized in this quote from an 86-year-old mother: *"I never thought my son would outlive me. What will happen to him when I am gone?"*

Rather than address this issue as singular aging service agency, Lifespan reached out to local disability service providers including the Al Sigl Center, our community's best known disabilities advocate and shared services provider for disability agencies, and the Arc of Monroe, a large provider of services for people with developmental disabilities. They too had noticed the issue, and had begun thinking about starting a service to meet the need. Instead of starting competing services, the three organizations approached the B. Thomas Golisano Foundation with a request for a planning grant to investigate the issue and to develop a collaborative local response.

In 2001, the Golisano Foundation funded a nine-month planning process, which included Lifespan, five member agencies of the Al Sigl Center (the Arc of Monroe, CP Rochester, the National MS Society Upstate NY Chapter, Rochester Rehabilitation & Rochester Hearing & Speech) and the University of Rochester's Department of Community and Preventive Medicine. The framework included national research and local focus groups. At the end of nine months, it was clear that:

1. No other local agency was helping families plan for the future care of their loved ones.

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2. The need was real, and it was growing.
3. A collaborative approach would be the best solution for this issue.

In 2002, the B. Thomas Golisano Foundation provided partial funding for Future Care Planning Services (FCPS).

Program Goals

The following goals and many more relating to productivity, efficiency and customer satisfaction are set on an annual basis and reported quarterly in an agency report. The program has exceeded its goals for the past five years. The combined totals are as follows:

- To complete 710 comprehensive plans to insure the future of a loved one with a disability. Staff completed 714 = 106% of the goal.
- To complete 345 17A guardianships for folks with developmental disabilities. Staff completed 438 = 127% of the goal.

In June of 2009, the program launched the Future Care Community Pooled Trust. The trust provides a convenient and economical way to have trust funds administered for people with disabilities. The program staff enrolled 31 people into the trust during that year. The staff then began setting goals around numbers of participants that would eventually help reach sustainability. In 2010, the program had a goal of enrolling 50 new participants in the trust, it ended up enrolling 80 new participants reaching 160% of the goal. The trust currently handles 160 clients with a pooled total of \$868,000.

Program Description

The mission of Future Care Planning Services (FCPS) is to create a comprehensive and coordinated system for life care planning and service for, and with, people with disabilities, particularly those with aging caregivers. This program has developed a four part planning process as follows:

1. Initial meeting with families and enrollment.
2. Create a letter of intent. This letter, intended to be a legacy of love, is a biographical profile that includes: the precise nature of the disability, medical history, abilities and limitations, likes and dislikes and daily routine of the person with the disability. This document is intended for use of new caregivers when the primary caregiver is no longer there to advocate for their loved one.

3. Development and Presentation of the Plan. The plan is developed by working one-on-one with caregivers and the person with the disability, when appropriate.
4. The plans are developed and encompass: legal options for planning (i.e., health care proxy, power of attorney, guardianships); financial tools (supplemental needs trust options, financial management; burial planning and caregiver estate planning for the benefit of the person with a disability); entitlement assessment and help in accessing these entitlements (i.e., SSD, SSI, food stamps, Medicaid, employment training); housing options; service coordination/social work services to link to community resources. The program staff has found that planning needs vary widely and that each person's situation is unique. The development of the plan takes approximately 3 months. Once the plan is written and presented to the family, the follow up phase begins.

Follow up tracking, includes efforts to determine individual patterns, and continues to be valuable for Future Care Planning Services. It provides an opportunity for staff to interact with and assist families who have completed their planning work. It also helps staff to better target post plan development resources since the cohort of families continues to increase in size and vary in need.

Timeline

In 2001, the Golisano Foundation funded a nine-month planning process, which included Lifespan, five member agencies of the Al Sigl Center (the Arc of Monroe, CP Rochester, the National MS Society Upstate NY Chapter, Rochester Rehabilitation & Rochester Hearing & Speech) and the University of Rochester's Department of Community and Preventive Medicine. The framework included national research and local focus groups. At the end of nine months, it was clear that:

- No other local agency was helping families plan for the future care of their loved ones;
- The need was real, and it was growing.
- A collaborative approach would be the best solution for this issue.

In 2002, the foundation provided funding for Future Care Planning Services (FCPS). Its mission is to help aging caregivers develop written health, housing, legal,

financial and guardianship plans pertaining to the future care of their loved ones with disabilities.

Financial Issues

The program originally received a planning grant of \$125,000 to do the research and start the program. Currently, the program is sustained by private foundation grants, New York State (Options for People with Disabilities) grant, United Way of Greater Rochester and fee for service. The program has sustained recent funding cuts from the state grant and the United Way. The program is fortunate to have continued Golisano funding support that helps it get through these challenging times. The program is always seeking new funding sources either through private funding or foundation donation. As a program is has continued to grow both service offerings and staff. We currently have 6 full time employee positions, with an overall budget of \$570,000.

Staffing

Each of the three agency executives serves as the advisory board. The day to day program has been managed by its Program Director since its inception in 2002. The Executives meet with the Program Director on quarterly basis. At the outset of the program, there were only two FTE's: the Program Manager and the Planning Specialist. The program has grown considerably since that time taking on eight new employees.

Partners

Future Care Planning Services is a legal joint venture between Lifespan, Al Sigl Center and Arc of Monroe County. The three agencies involved in this collaborative are 501(c)(3) organizations. Al Sigl Community of Agencies provides first-class custom-designed space, shared business services (e.g., HR, IT, telecommunications), and awareness-building and fundraising to add capacity for the partner agencies which serve 60,000 children and adults with disabilities. Lifespan is Monroe County's only comprehensive agency serving older adults and their caregivers by providing education, training, advocacy and a continuum of non-medical direct services that mirror the aging process. The agency responds to the needs of both frail and healthy older adults, as well as caregivers of any age. The Arc of Monroe County works with and for individuals with mental retardation and/

or developmental disabilities and is a recognized leader in New York State in providing innovative, effective, and responsive services based on the individual service model and the cooperation of program participants

Outreach

In the initial stages of the program, the program staff reached out only to the three lead agencies along with the other agencies that participated in the initial conversation about the need in the community. Initially the Program Director held one on one interviews with the case managers to talk about what specific issues they were experiencing with their families. The Program Director developed a presentation to be used in group settings and with individual families. Once the program had a few families into the process, it began a broader outreach to other disability agencies in town. A brochure and public service announcements and a website were developed in 2005-2006. The program launched a new and improved website in September of 2007 with the assistance of the Ad Council of Greater Rochester. The program did not experience the great impact that it anticipated from a television campaign, and has always found that it receives better results from written word and word of mouth. Therefore, Future Care does constant outreach to local aging and disability organizations. The program has received referrals from more than 70 organizations in the greater Rochester area. Program staff makes the rounds once a year, to every major disability organization. The data tells us that although many professionals have seen multiple presentations over the years, they still report an increased understanding of the program and appreciate the refresher aspect of the outreach. The program is also open to and encourages community support groups to invite staff in to present directly to families.

Diversity

The program serves all disabilities, people of diverse ethnic backgrounds, age and gender. The program believes that each person has inherent dignity and inalienable rights. It utilizes a person- and family-centered approach that respects cultural diversity and lifestyle differences in all our interactions. The staff believes that life care planning is important for all persons with a disability. Planning should be provided in a nonthreatening, non-judgmental and respectful manner.

Challenges & Barriers

The Future Care Planning Services model has changed over the years. As the program has encountered challenges such as the plans taking too long to complete, fee structure not supporting the need of the program, adapting the policies and procedures to meet the demands of different funders, etc. The program has always had the ability to look at the situation, analyze the data and make changes based on the findings received. It has gone through several “rapid cycle” processes which are based on the Six Sigma model. These have been extremely effective in helping them to keep up the ever growing demand for the service.

One of the greatest challenges has been implementing and maintaining a “fee for service” model within the OPWDD system. Historically, families receiving services through OPWDD have not been expected to contribute financially for any services that they receive through the system. Interestingly, families with loved ones of all other disabilities expect to have to pay and are pleasantly surprised at the low cost of the service. The program has endured foundation and state cutbacks, but it has made the staff more motivated to help families understand the importance of some contribution to the process.

The program has been challenged by not having enough funding to hire the staff necessary to handle the workload. At a critical juncture, the team decided to restructure the work load so that it could hire for the trust accountant position and cut the administrative position. This required that all staff take on additional duties to cover the administrative duties required by the program. The success of this program can be directly credited to the pride that the team takes in the program and the high work ethic that they display every day of the week.

Program Evaluation

At the inception of the project, an independent Evaluation Consultant was brought into the project, and continues to work with the program to monitor trends and impact. In the first stage of the process, clients are assessed to determine areas of need. The Letter of Intent and Plan are developed and presented. The program tracks all activities completed prior to the presentation of the plan and all suggested activities for the family to follow through with. At the Presentation of the Plan, the final meeting with the team, the clients are asked to fill out an anonymous “satisfaction survey” and

place it in an envelope. The surveys are forwarded to the evaluation consultant. The follow up calls occur at 3, 6, 12, 18, and 24 months after the plan is presented. The customer is specifically asked questions about completed activities and barriers to planning. The staff continues to support and guide the families in meeting their planning goals throughout this period. This data is tracked throughout the planning and follow up phases. All data is compiled and analyzed by the evaluation consultant and presented to the Executive Committee on an annual basis.

Satisfaction is exceptionally high. Follow-up surveys indicate that more than 90% of respondents have implemented suggestions from their plan at the 24-month follow up call. Ninety-five percent of respondents report that planning has produced daily living changes that improved the loved one’s life at once. An astounding 99% of the families report that they would recommend Future Care Planning Services to a friend.

Lessons Learned

If you provide your clients with the best possible customer service, you will have the best possible outcomes. The greatest challenge has been ongoing realization that serving families in this personal and emotional arena can be very messy. Families come in all shapes, sizes and situations. The program strives to be non-judgmental and supportive in all we do. One lesson learned however, is that not all families are ready to engage in this process. From the inception of the program, staff has worked with approximately 17 families per year that have been unable to follow through with the planning process. Many of them have complicated personal and legal issues that stand in the way of progress. Program staff has learned to identify these families and move them “inactive” until they are ready, or their issues have been resolved. Another lesson learned, that it is the best interest of the program not to spend inordinate amounts of time, when there is likely not going to be a positive outcome. Program staff is always willing to (and have on many occasions) brought families back into the program when time is right.

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Drop-In Respite and Caregiver Cooperative

Asian Community Center
Sacramento, California



In the Asian Community Center's Drop-In Respite and Caregiver Cooperative Program caregiver-volunteers "earn and buy" respite time with other Co-op members, sharing their care giving methods and engaging in self-learning, while building a community resource.

Background & History

The Asian Community Center of Sacramento Valley, Inc. (ACC) is a private non-profit tax exempt 501(c)3 corporation established in 1972 and its mission is to promote the general welfare and enhance the quality of life for our community by identifying, developing, and providing culturally sensitive health and social services for older adults.

Program Goals

In addition to promoting health and wellness, program activities are used as opportunities to identify and address specific service needs among older persons and their family caregivers.

Program Description

Initial efforts of the organization focused on building capacity in the community, which resulted in the formation of over fifteen service programs and civic organizations responding to a range of needs among youth, young families, immigrants and refugees, underemployed and unskilled workers. Several of the organizations formed continue to serve the community today. The first major project was the ACC Nursing Home, completed in 1987. Community needs assessments in 1990 and 2001 studying eleven Asian ethnic groups in Sacramento pointed to an ongoing need for social and cultural programs as well as support services for older people. The purchase of a building led to the inception of the ACC Lifelong Learning and Wellness Program (LLWP) in 2002.

Staffing

ACC Respite, like all other ACC programs is managed by a program manager, with oversight by the COO.

Staff include two program assistants and a CNA. Volunteers make up the bulk of the Respite workforce, as many of our participants, which currently average 26-30 each day, are wanderers and require almost one-on-one supervision.

Partners

Respite also presents information and assistance for elders and family caregivers on understanding how service systems work, enabling them to be more confident consumers. ACC coordinates other support services for caregivers, such as with the LLWP. LLWP activities are focused on mainstream or Eastern approaches to health and wellness for caregivers and community members. LLWP and Respite are located in the same building, so many caregivers take health and wellness classes while their loved one is in Respite. Respite also coordinates with ACC Rides Transportation Services; more than half of Respite participants are met at their doorway and safely driven to and from the program by ACC Rides drivers and escorts. ACC took the lead in organizing Sacramento's only home and community based network of senior and caregiver organizations: the Asian Pacific Islander Family Caregiving Services (APIFCS). ACC hosts monthly caregiver forums or support groups by APIFCS members, Parkinson's Association, and Alzheimer's Association.

Other significant collaborations include sustained partnerships with A4AA, which has awarded the program a \$25,000 grant annually, advocacy organizations, and organizations such as California State University, Sacramento's Kinesiology Department, which recommends Drop-In Respite as an internship and special projects site. Respite shares clientele with the City of Sacramento's Triple R Adult Day Care program; both programs share information related to care receivers and families, and do some cross-programming. New in 2009 was the incorporation of some Legacy Corps (AmeriCorps) members as volunteer caregivers. The Legacy Corps also provide in-home respite to the participants. A major partner for ACC Respite is the Bridge to Healthy Families- Asian Pacific Islander Dementia Care Network, a collaboration of ACC, Alzheimer's Association, and University of California Davis Alzheimer's Disease Center. The Network provides care consultation and case management, as well as community and caregiver training and

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resources. This coordinated and collaborative approach to caregiving provides multiple services and supports for the caregivers, the recipients of care, and the families as a whole. Networks and friendships developed and maintained by families' participation in Respite and other programs mediates the "burden" of caregiving, ultimately strengthening the caregivers and communities themselves.

Outreach

The program targets API elders, many whom speak limited English. However, like all ACC programs ACC Drop-in Respite is open to all seniors. ACC has been a source of services for the API community for over 30 years, and is recognized for addressing cultural needs of the community. Word-of-mouth continues to be the most effective outreach tool. Other methods used to conduct outreach include *ACC News*, ACC's quarterly newsletter distributed to over 10,000 households; ACC website: www.accsv.org; Facebook; and through the Asian Pacific Islander Family Caregiver Services (APIFCS)—a collaboration of direct service organizations with a common goal supporting the needs of caregivers in the API community by sponsoring events, collaborating on projects, and providing a supportive network to members. ACC staff conduct outreach at several large (i.e., Pacific Rim Festival, Filipino Fiesta, and Chinese Harvest Festival) and smaller (i.e., Land Elementary Community Health Fair and Elk Grove Senior Center Fair) community events throughout the year. Outreach efforts focus on Sacramento County families whose members include low-income elders, limited-English speaking elders, and those with physical and /or cognitive disabilities such as dementia or Alzheimer's.

Challenges and Barriers

The 2001 needs assessment with over 60 interviews showed few Asian Americans self-identifying as family caregivers. However, listening to LLWP participants talk about their family situations revealed that over two thirds were active caregivers of an older family member. Research shows caregiving burden as a common reaction to being a caregiver. Despite potential negative consequences, many Asian Americans will not seek help with caregiving. Individuals perceive their caregiving as being a "good" daughter or son rather than a distinct role signaling a need for assistance from service

providers. In many Asian cultures, the value of "filial piety" is manifested by adult children believing it is their duty to take care of aging parents, no matter what the emotional, physical, or financial toll.

Cultural notions of shame and stigma prevent many from seeking help for health conditions deemed "private family matters" (Sue, 1993). ACC addressed cultural and other barriers to help-seeking by listening to family caregivers and in collaboration with them, developing a program that was culturally acceptable, ACC Drop-In Respite ("Respite"), in April, 2003. Staffed with a program assistant and CNA, Respite provided one day a week of service for family members with a functional or cognitive disability. The program targeted families who had cared for an elder for longer than a decade, but who had not found other services helpful and affordable. Caregivers could drop off their loved one or could stay and take part in the daily activities.

A few months after the start, caregivers requested a second day of service. Lack of funding prevented this. With staff support, caregivers and volunteers organized to make another day available by forming a cooperative, whereby family caregivers exchanged volunteering for their care receiver's attendance. In recognition of this new dimension, the program was renamed the "ACC Drop-In Respite and Caregiver Cooperative."

The only day respite cooperative in the country, at ACC Respite, caregivers collaborate with staff to plan and implement program activities twice a week. Focused on the experience of participants, caregivers, and volunteers, the program fosters enjoyment of each day, engenders social interaction, promotes safe, stimulating, and healthy mental and physical activity, and provides an environment to learn new coping skills. Another innovative aspect is the Caregiver Council, comprising caregivers, volunteers, and staff, which meets monthly to address issues concerning the program and also acts as a support group. Accordingly, caregivers are empowered to make decisions affecting themselves, the care receiver, and the program. Open to all, our approach provides a culturally appropriate and culturally acceptable service for Asian American families in particular, while keeping sessions affordably priced at \$25, including lunch. Therefore, the program is distinctive in many ways. While it is one of only a handful of respite programs specifically targeting Asian Americans it also serves Latinos, Caucasians, and African Americans. Staff and volunteers speak more than 7 Asian languages and

dialects, in addition to English, German, and Spanish. Asian themed activities are part of the program, along with activities celebrating other cultures.

ACC Drop-In Respite and Caregiver Cooperative is innovative in other ways. ACC focuses on community building through activities involving older adults (caregivers and others) sharing valued skills and talents as volunteers and mentors to younger volunteers. The importance of volunteers is exemplified in the efforts of Fred Furukawa, a retired kinesiology professor who developed Respite's fitness program. Fred took elements from tai chi, yoga, stretching, strength training, and fitness programs, modifying the movements to fit the abilities of Respite participants and integrates physical, mental, social, and kindred connections consistent with their life experiences. At Respite, Fred leads a 45 minute fitness activity for care receivers and trains caregivers on ways to guide them through specific movements. Thus, family caregivers are furnished with tools that enhance their caregiving capacity and help them take care of their own health.

Program Evaluation

Before the development of Respite, there was a lack of culturally appropriate and culturally sensitive programs in the area. Existing programs did not offer services for a multicultural population, such as new immigrants or non-English speakers. Other barriers to service including the above-mentioned cultural barriers or perhaps ignorance of services available combined to result in a severely underserved community. Annual program evaluation results show Respite successfully meeting community needs, as results from the 2011 survey caregiver respondents (n=20), indicated 60% being "very satisfied" with the program, and 40% "satisfied" or "somewhat satisfied." Only two respondents listed taking part in another respite or adult day program. Responses to "what do you like about Respite" include: "the level of care they provide" (60%) and "the participants," "the languages spoken there," they serve Asian food" (50% each). Interestingly, 50% also chose "I am able to volunteer there." This indicates that our model of caregivers attending respite with their care receiver and the corresponding philosophy that respite can also be thought of as spending time with the care receiver in a supportive milieu, resonates with half of the respondents.

Lessons Learned

The keys to our success are manifold. The cooperative idea stemmed from women who had swapped babysitting duties years ago. The program is sustained by dedicated staff and family caregivers, who volunteer their time and donate financial and material goods. The Caregiver Council helps give caregivers ownership of the program, and also serves as a support group. The timing of the Caregiver Council meetings allows Caregivers to attend while their family member is in Respite. Of course, having reliable volunteers of all ages also helps the program keep going. While caregivers are supposed to volunteer one time per month, some volunteer many more hours and, in addition, send other family members to volunteer. During the summer some middle school, and many high school and college students volunteer every day in respite as "internships," or to meet school volunteering requirements, or just because they want to be around their grandparent. Volunteer orientation and training, including "on the job training" by experienced volunteers keeps the program running smoothly. Another lesson learned is that monthly newsletters and mailed reminders to contribute the "suggested donation" leads to more donations in support of the program and greater participation levels at Council meetings and other events. Finally, staff has also learned to celebrate more with our participants. Monthly birthday parties, Mother's Day, Father's Day, and other special events, as well as varying entertainment keep participants happy and engaged. Our annual Caregiver Dinner in November allows caregivers and care receivers to go out together to dinner, and enjoy fun and games and entertainment in a welcoming, supportive environment.

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Time Out Program

Center for Intergenerational Learning
Temple University
Philadelphia, Pennsylvania



The Time Out Program mobilizes college students to provide in-home respite services to caregiving families throughout the Philadelphia area.

Background & History

The *Time Out* Respite Program is sponsored by Temple University's Intergenerational Center, a national leader in bringing together diverse communities and generations to address critical social concerns and in creating opportunities for lifelong civic engagement. The Center's mission is accomplished through creating innovative, intergenerational programs; providing training and technical assistance to help practitioners effectively utilize intergenerational approaches to address community needs and engage diverse groups in service. Also, the Center conducts local and national research and evaluation initiatives that assess the efficacy of specific intergenerational interventions, such as the health literacy needs of older immigrants, and examines civic engagement among the 50+ immigrant population.

The *Time Out Program*, which began in 1986, is an innovative intergenerational model for low-cost in-home respite care for families caring for elderly relatives living in Philadelphia. *Time Out* matches college students with the frail elderly to provide caring companionship, supervision and assistance with activities of daily living. Students are paid \$8/hour as compared with the average agency rates of \$11 to \$19/hour, resulting in substantial savings to families.

Program Goals

Time Out is designed to meet Philadelphia's need for low-cost, consumer-driven, in-home respite care. This unique model, in which *Time Out* staff brokers relationships between caregivers and a diverse group of trained college student respite workers, promotes the ability of the elderly to continue living in the community and maximize the quality of their lives.

Program objectives are to:

- Provide high quality, affordable respite services for at least 10,000 hours to a minimum of 110 families a year;
- Provide free respite services to 20% of caregiving families;
- Recruit and train 100 student respite workers;
- Reduce the stress experienced by caregivers;
- Increase the opportunity for older adults to remain living at home;
- Decrease the social isolation of frail older adults; and
- Increase the students' interest in pursuing careers in gerontology and community service.

Program Description

The *Time Out Program* is an innovative, low-cost resource for personalized respite care for families caring for elderly relatives living in Philadelphia. *Time Out* recruits, trains, and matches college students with the frail elderly to provide companionship, mental stimulation, and assistance with activities of daily living. Students do not provide personal care, house cleaning, or driving services. Families pay students directly \$8/hr, a rate less than half of home health care agencies. For the past twenty-five years, this program has succeeded in enhancing the quality of life for caregivers and their frail older loved ones. Each year, approximately 110 families receive over 10,000 respite hours from student respite workers who are carefully screened, trained, and supervised. Additionally, approximately 40 families are screened and referred elsewhere. *Time Out* fosters the development of unique relationships between care recipients and students. Since one student is paired with a family for at least a semester, a close bond usually develops. *Time Out* requires only a 2 hour minimum per visit, thus allowing caregivers with limited resources an opportunity to schedule regular, short respite breaks. Participating families consistently report reduced stress from caregiving responsibilities and more time for themselves. Elderly care receivers feel less isolated and love the opportunity to interact with students. Students gain a better understanding of their own families, a heightened respect for the elders, and overall personal and professional growth.

Timeline

At the beginning, Time Out recommends an initial period of six to nine months to design the program, build community awareness, and establish a core number of university faculty contacts from area schools, referral agencies and health care providers. This outreach can be performed while the program content is being developed.

Financial Issues

During the initial development and launching of the program, sufficient funds are needed to cover the salary of a full time director. Other necessary expense categories include: travel, postage, training, including handouts and food, computer, printer, copier, fax machine, telephone, and office supplies. The Time Out Program has grown significantly from the early years of serving approximately 50 families to the current provision of services to more than 110 families per year. Additionally, although Time Out and The Intergenerational Center are housed at Temple University, the programs are all fully dependent on external funding. In order to remain viable, Time Out counts on the receipt of outside funds to sustain its annual operating budget. Financial support comes from a number of local foundations. It is extremely challenging to maintain funding since foundations have fewer funds available due to economic losses in the stock market. It has, therefore, been necessary to make adjustments to the budget by cutting certain line items. The program does not receive any state or federal funds.

Staffing

Program Director (50% Effort)

Responsibilities include: 1) oversight of the program operation; 2) supervision of the Program Coordinator; 3) outreach to the community and publicizing *Time Out*; and 4) fundraising.

Program Coordinator (100% Effort)

Responsibilities include: 1) recruiting, training, and supervising respite workers; 2) conducting initial phone assessments of service requests; 3) making home visits to match students with families; 4) ongoing care management and monitoring of student matches; and 5) providing ongoing support to students and families.

Student Internship (8 hr per week)

Responsibilities include: 1) conducting phone surveys of

caregivers; 2) entering data received from caregivers and students into the database; 3) preparing training folders

For more than 23 years, one full time staff person was responsible for maintaining all aspects of the program, with the addition of limited financial management support from the Intergenerational Center. As the program has grown to serve more families and train more students to meet this demand, it was necessary to hire more staff. Two years ago, the staff was expanded to include the addition of a half time person. Currently, one full time and one part-time staff are accountable for program operations and fundraising.

Outreach

Families caring for frail older adults who reside in Philadelphia are eligible for services. An identified caregiver must be present at the initial home assessment visit and maintain on-going, open communication with the Time Out staff and student respite worker. Caregivers may live in the same home as the care receiver or elsewhere. Referrals come from key agencies serving older adults, including: Philadelphia Corporation for Aging, the Alzheimer's Association, home health care agencies, medical social workers, geriatric practitioners, adult day care centers, Meals on Wheels, and area Naturally Occurring Retirement Communities. Past and current consumers of Time Out services regularly refer relatives and friends for assistance. Other important marketing tools are the program website, brochure and flyers.

Diversity

Time Out targets caregiving families whose frail elderly relatives live in Philadelphia and who are experiencing the need for in-home respite care services. The program reaches across cultural, racial ethnic and gender differences, and does not discriminate based on any of these attributes. The program serves older adults with wide range of medical problems that include Alzheimer's disease and other dementia, Parkinson's disease, depression, stroke, arthritis, osteoporosis, diabetes, vision/hearing impairments, cardiac, pulmonary, renal, and bone fractures. Approximately, 50% of those served have Alzheimer's disease or other type of dementia.

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Challenges & Barriers

The greatest challenge to the program is sustainable funding. Staff is constantly researching new and renewable sources of funding, writing grants, and instituting other means of funding such as a fundraising letter to past and current consumers. The latter resulted in over \$2,200 in donations last year. Other challenges encountered are the need to rematch families when the student is no longer available, the lag in students' response to our communication requests, and the resistance of the older care receiver for services. There is often a gap at the end of the semester to provide services to new families because all the students have been matched. It is, therefore, necessary to create a waiting list until another group of students is trained.

Program Evaluation

Formal evaluation protocols and survey instruments used to elicit qualitative and quantitative data outcomes are the Quality Assurance & Home-Based Respite Satisfaction Tool; the Zarit Caregiver burden scale to evaluate the program's impact on reducing caregiver stress; the Expanding Service Learning in Elder Care instruments to assess impact for students on increased geriatric knowledge and career choice in aging; transcripts from student focus groups; and program evaluator in-depth interviews with participating students.

Lessons Learned

Working with students can at times be challenging. It is important to recognize that students have hectic schedules with many other commitments related to school work, part-time jobs, and other extra-curricular activities. It may take multiple contacts through e-mail and phone calls to communicate with them. Occasionally, an older person is resistant to accepting services. It is important to handle this with a low key approach. The family is encouraged to schedule a home visit regardless of this attitude. Once he/she meets the student or has one or two visits, the care receiver's resistance seems to erode.

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Memory Mobile: Innovative Strategies for Outreach to Rural Alzheimer's Caregivers

Alzheimer's Association—FL Gulf Coast Chapter
Pinnellas Park, Florida

alzheimer's association™

This program provides the only mobile Alzheimer's disease support and education service delivery vehicle in the country to reach rural caregivers caring for persons with dementia.

Background & History

While the ability to reach and provide services to people living with Alzheimer's disease and their caregivers throughout the service region was a priority to the Chapter, it was neither fiscally nor service effective to create enough physical offices to reach and support the Chapter's rural services regions while maintaining sufficient services to meet the demand in the Chapter's more densely populated, metropolitan areas. In 2001, the Chapter addressed this challenge by documenting the need for and then obtaining private donations and public funding through the State of Florida to create and implement what is now known as the Memory Mobile, which provides outreach education, care consultations, memory screenings and caregiver education targeting low income, rural, isolated and/or inner city people living with Alzheimer's disease and their caregivers.

Program Goals

The target population for the Memory Mobile is underserved and/or isolated families dealing with, or at risk for Alzheimer's disease or a memory related disorder in 17 counties along the Florida Gulf Coast. An estimated 197,000 persons with Alzheimer's disease live in this 17 county region. The overall goal is to provide the care, support, and education needed by caregivers of persons with Alzheimer's disease to delay institutionalization.

Program Description

The Memory Mobile, which is a 30 foot Winnebago with room for 14 people and a wheelchair lift and accessible bathroom, provides memory screens, outreach education, care consultations, information services and streamlines those impacted by Alzheimer's disease into ongoing medical care and support systems. Many Alzheimer's caregivers are truly isolated and do not have

the ability to leave their loved one to come to an office or drive hours to a memory screening site. Research clearly indicates that Alzheimer's caregivers are at a much greater risk for a variety of health problems including depression, poor nutrition, anxiety, cardiovascular problems, high blood pressure and physical injuries than non-caregivers in their age groups. One in eight caregivers becomes ill or injured as a direct result of care giving. The Memory Mobile increases our ability to reach those most in need of services to prevent and/or reduce these issues.

Timeline

Funding was obtained in 2001 to implement Memory Mobile which is still operational today.

Financial Issues

The Memory Mobile is funded through a mixture of public and private funds.

The State of Florida has been a significant funding source from the program's inception. Since Florida's public funding has been on a sharp decline, the Chapter is shifting to private funding from community foundations and private grants. In addition, the Chapter has implemented a corporate sponsor program, with logo opportunities and has put in place a fee per request system. The total yearly budget for Memory Mobile is \$150,000.

Staffing

Memory Mobile has three full time employees: one driver with a chauffeur's license and two Program Specialists.

Outreach

Memory Mobile expanded its outreach through memory screens from 13 different memory disorder clinics serving 67 counties.

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Caregivers' Guide for Bone Marrow/Stem Cell Transplant

National Bone Marrow Transplant Link
Southfield, Michigan

nbmtLINK

National Bone Marrow Transplant Link

The Caregivers' Guide for Bone Marrow/Stem Cell Transplant was developed to educate loved ones about their vital role through the experiences and perspectives of fellow caregivers.

Background & History

The National Bone Marrow Transplant Link (nbmtLINK) program is based in Southfield, Michigan and was developed by volunteer advisors and reviewers from Barbara Ann Karmanos Cancer Institute, The National Marrow Donor Program, The University of Pittsburgh Medical Center, Mayo Clinic Cancer Center, and the University of Michigan Health System. nbmtLINK is positioned to meet the growing needs of bone marrow/stem cell transplant survivors and their caregivers. The program is seen as a national leader in the patient education and advocacy community.

To focus on the emotional and support needs of BMT caregiver, nbmtLINK created a publication called *Caregivers' Guide* dedicated to helping prepare bone marrow transplant (BMT) caregivers for this important role. The original version was published in 2003 and was revised in 2007. For the second edition, one staff person devoted a great deal of time over the course of nine months to this project and is the mother of a transplant survivor and served as her daughter's caregiver.

Program Goals

It is estimated that there are over 100,000 current and past BMT caregivers in the U.S. An estimated that 20% have been reached through the *Caregivers' Guide* publication and nbmtLINK's Website. The goals of this program include: recognizing the role of the BMT caregiver, promoting the involvement of the caregiver, encouraging others to support the work of the caregiver, and overall wellness for the family caregiver.

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Program Description

This program provides practical perspectives and advice on nine different topics that a BMT caregiver will find relatable. It also includes a list of resources for caregivers, such as organizations, books, websites, and videos/DVDs. In addition, the booklet provides information about the Peer Support on Call for Caregivers, a free service offered by nbmtLINK. This program provides emotional support through one-on-one conversations with trained peer support volunteers, caregivers themselves, who have successfully faced the BMT experience and cared for their loved one.

Timeline

The major steps in developing this publication include: recruiting writers and reviewers, writing, editing, organizing into chapters, recruiting sponsors, communication with the printer, marketing and coordinating the distribution of the booklets. Overall this process takes nine months.

Financial Issues

The overall budget for this program was \$30,000. This included printing 20,000 copies, staff time, and shipping/postage. The program is sustained through charging \$10 for each booklet and bulk orders from hospitals. Those who can't afford to pay are provided free copies. Financial assistance was also received from 23 medical centers and BMT-related organizations. The program also receives contributions from individuals, corporations, and foundations. Fundraising for the non-profit organization continues to be challenging, especially in this current economy. The staff needs to spend an increased amount of time to fundraise which consumes the time that they need to develop and implement programs for patients and families.

Staffing

For the second edition of the booklet, the program had one staff person who devoted approximately 75% of her time to the project over the course of three months. The Executive Director spent a great deal of time overseeing the project. At the outset, the program utilized staff that was proficient in recruiting writers, reviewers and editing submissions, and organizing the booklet into chapters. Once a draft of the booklet was prepared, staff needed to communicate with the printer in terms of cover art and layout. Currently, the program has

a weekly volunteer who fulfills orders and handles shipments of the requests for booklets.

Partners

The program relied on advisors and reviewers from the Barbara Ann Karmanos Cancer Institute, the National Marrow Donor Program, the University of Pittsburgh Medical Center, Mayo Clinic Cancer Center, and the University of Michigan Health System. Individuals from these institutions provided valuable content guidance.

Outreach

Caregivers are reached through the program's participation at national conferences, the nbmtLINK website, online enouncements, the use of online surveys, and the health professionals at the 20 Transplant Centers who have become nbmtLINK Partners.

Diversity

The guide provides perspectives of BMT caregivers from different racial, gender, and age groups.

Program Evaluation

A survey was distributed in order to evaluate the publication. Of the responses received, the majority felt that the publication offered practical strategies for coping and found it educational. Eighty-three percent of respondents said they would recommend the publication to others. The publication was distributed to over 1,000 health professionals across the U.S. with the option to return an addressed, stamped card to provide feedback. Requests for additional publications and 71 responses were received. This was a lower response rate than desired so a new plan was developed to distribute the remaining copies. Statistically the response for feedback was lower than anticipated; anecdotally there were many positive comments from health professionals and caregivers alike.

Lessons Learned

The biggest lesson learned was that there was tremendous interest in the "caregiving" aspects of health care. The booklet, specifically directed at BMT caregivers, was the first of its kind. The program also learned that when working with several authors, the structure and expectations of the project need to be clearly defined. With 10 different authors, clear

communication and coordination was needed on an ongoing basis so that the project could be completed in a timely manner.

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Online Caregiver Support Groups

CancerCare
New York, New York



Online Caregiver Support Groups provide virtual 24/7 access to support and information for people across the country caring for a loved one with cancer.

Background & History

CancerCare is a national nonprofit organization founded in 1944 whose mission is to provide free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare provides support to cancer patients and their loved ones through the following services: counseling, education, information, financial assistance, practical help, and referrals to additional resources.

Staffed by oncology social workers, CancerCare's clinical services are the cornerstone of its mission. CancerCare has long recognized that caregivers provide important and constant emotional and physical care to the person with cancer and that it is important to support caregivers. The Online Caregiver Support Groups combine the expertise of CancerCare's professional, master's level oncology social workers with advanced technology. Hosted on our website, our online support groups take place in a message board format which, unlike chat-format online support groups, allows participants to reflect on others' posts and thoughtfully craft their own, on their own terms, within the time they wish to devote to them based on a 24/7 availability. This extended period of time enhances the quality of participants' experiences in the online support group environment. Online support groups are an especially important source of support for caregivers living in rural areas and for working people who are unable to take the time to participate in traditional face-to-face support programs, in addition to the time devoted to caring for their loved ones with cancer.

Program Goals

The online support groups provide a forum for caregivers to obtain support, to learn coping strategies, and be informed about treatment advances. Participants in CancerCare's Online Caregiver Support Groups find

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that they are able to improve their ability to manage their loved one's cancer diagnosis, treatment, post-treatment issues, or the loss of a loved one, while sharing valuable coping strategies, insights, and resources with others. Participants also report that the groups relieve the isolation and loneliness they sometimes feel while giving so much of themselves to the needs of their loved ones with cancer.

Program Description

The online support groups utilize an internet-based message board format, accessible only by password to registered member. The message boards are moderated by our oncology social workers and are accessible to members 24 hours a day, seven days a week to provide them with a forum for sharing information and providing each other emotional support. The online format enables caregivers to reach out to one another from any part of the country to obtain help from experienced oncology social workers, and to connect with other caregivers to share experiences and lend emotional support. Examples of the types of online support groups offered include: *General Caregivers (multiple sections)*, *Lung Cancer Caregivers*, *Young Adults (age 20-40) as Caregivers*, *Parents of a Child with Cancer*, and *Pancreatic Cancer Caregivers*.

Timeline

CancerCare's Online support group's run in 14-week cycles with two-week-long breaks in between for screening, registration, evaluation, and planning. One challenge is to identify a critical mass around which to build a group. Program promotion activities are important and need to be varied.

Financial Issues

Initial start-up costs related to hardware and software, and of course, staffing. The program requires a manager, social work moderators, and a website manager. Other costs are associated with outreach and recruitment as well as website maintenance. On-going funding sources have varied including corporate sponsors and foundations. At times the program offerings are spurred by foundations with a specific diagnostic emphasis, e.g., breast cancer or brain cancer. While CancerCare does not receive government support, the economic climate does have a ripple effect on the ability of these groups to fund new initiatives.

It is estimated that the up-front cost to replicate this program would be greater than \$100,000.

Staffing

The program is managed by a full-time Online Support Group Manager who is a licensed clinical social worker, and a full-time Group Program Database Manager. As the program continues to expand, the services of an additional oncology social worker was added to assist at 40% of the full time employee.

Partners

CancerCare enjoys collaborative relationships and partnerships with many other organizations in the cancer community. The newest partners include the L'Oreal/Paris Ovarian Cancer Research Foundation and the Triple Negative Breast Cancer Foundation.

Outreach

CancerCare receives 1,500 calls into its national toll-free Hopeline on a weekly basis and this is an important mode to connect people to our clinical services. In addition, services are promoted via targeted mailing campaigns, as well as via our newly redesigned website.

Diversity

CancerCare employs a diverse workforce and also has ongoing professional development opportunities for staff on these topics. The Online Caregiver Support group programs reach people of both gender and all ages, and include people of African American, Asian, Latino, Caucasian and Native American origin. CancerCare has offered groups moderated by Spanish-speaking oncology social workers.

Program Evaluation

Program participants are asked to participate in quality and satisfaction surveys in which they provide valuable feedback. The following online support group participant testimonials illustrate the impact the program has had on the lives of caregiver of people with cancer:

I used to feel cheated...everyone asks about the cancer patient but not the caregiver. But this support group has filled that gap. And I think BECAUSE of this group, I now hear more people ask me how I am. Hard to explain...but, people DO ask...and I used to answer

with...”With Susan”...I was afraid to open myself up to people...open up to the pain. Having you all to share it with has enabled me to share it elsewhere. Julie

This is one of our last week’s together and I would just like to say what a special group this has been for me. One would think conversing via the internet would be too impersonal to make a difference. However, I would like you to know that many times this group shored me and touched my heart. Thank you! Joanne

Lessons Learned

It is important to have access to technology and administrative support and commitment to implement. The clinical aspects of the program need to be conceived and it is important to develop both a clinical manual for moderators, as well as a manual for participants.

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Old Order Amish Caregiver Program

Mid-Illinois Senior Services, Inc.
Sullivan, Illinois

The Old Order Amish Caregiver Support Program successfully provides support, counseling and training—with intense emphasis on cultural sensitivity to the Amish beliefs and ways—while overcoming obstacles that have historically kept the Amish from seeking help outside their faith.

Background & History

Mid-Illinois Senior Services is a not-for-profit organization located in the heart of Illinois Amish country. The program provides Caregiver Advisory services to a very rural population in a tri-county area. In 2004, when the program offered the first Powerful Tools for Caregiving classes, the staff was surprised to find those that came were all members of the Old Order Amish community. Thus, during this six-week course, a relationship grew and the tremendous need for caregiver support, education and counseling for this isolated culture was revealed. This was not a “planned” program in the beginning. The overwhelming response to the services came as quite a surprise. However, eventually a “planning” meeting was held at the request of the Amish Bishops and Elders of each church district to explain the program and “intentions.” After many meetings with honest discussions of cultural differences and how to work together, the Bishops and Elders granted the program staff “permission” to offer the caregiver services to the Amish community.

Program Goals

The Old Order Amish Caregiver Support Program is intended to provide support, counseling and training to caregivers of older adults in the Amish community.

Program Description

The Old Order Amish are a patriarchal, pre-industrial society who shun electricity, travel by horse and buggy and believe in simplicity and self-denial over comfort and convenience. Therefore, the goal of the program was to overcome the four major barriers for the Amish: isolation/lack of transportation, the need for confidentiality OUTSIDE the Amish community, lack of knowledge/access to outside resources and the strong belief in self-denial over comfort. The success of this program has been humbling. The growth of

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clients asking for 1:1 in-home counseling and attending support groups is nearly overwhelming. The Caregiver Advisor is now allowed to serve the Amish community with freedom to visit any caregiver in need, conduct support groups, trainings, informational seminars etc. This can be directly attributed to the level of trust and respect the Caregiver Advisor works hard to earn from this community. Amish women and men alike now turn to the program for help without hesitation. To quote one client, *“this is a great accomplishment for the Amish to be so open to someone outside of our people for help.”*

The program offers 4 key areas in which to support the Amish caregivers in their roles:

1. A confidential support group which meets monthly with transportation provided for all who are unable to come by buggy.
2. In-home 1:1 counseling for all caregivers and their families (it is typical for Amish households to have many caregivers and care receivers residing on one piece of land or in one household)
3. “Trainings” offered on 1:1 basis or in a group setting (such as Powerful Tools for Caregiving, learning coping skills for better mental health, managing caregiver stress, bereavement counseling, hospice education, and Alzheimer’s disease awareness)
4. In-home 1:1 mental health counseling. The program’s continued success is due to the focus on offering all services “in-home.” This is such an important factor to the Amish people because it respects their need for privacy and their belief that one’s family issues should not be in public for the world to see.

Timeline

The planning and implementation of this program continues to be handled with great caution. The need for being culturally sensitive at all times to the Amish beliefs and ways must take highest priority. It cannot be stressed enough that the implementation and success of this program stems from the importance of being sensitive and respectful to the Amish way. The Caregiver Advisor must dress appropriately when with the Amish (arms and legs covered), and relates caregiving counseling to Biblical principles, as Christianity is the determining factor for every day Amish life. The program also respects the patriarchal belief that women

are equal in importance but not equal in authority to men.

Financial Issues

This program is sustained through state and federal grant proposals, with oversight from the East Central Illinois Area on Aging. It also receives a 20% funding match from the community, proceeds from the Community Thrift store and starting in 2011 the program began receiving property tax referendum funding for Moultrie County. Regarding state budgetary reductions, the program has had to operate on a flat budget since 2004, while dealing with substantial increases in the client participation.

Staffing

This program is managed solely by the Caregiver Advisor. The Caregiver Advisor personally makes all home visits, conducts Support Groups, special seminars and trainings upon request (e.g., bereavement, Alzheimer’s awareness) and serves as mediator as needed for family/church meetings regarding difficult caregiving situations. From the beginning, and to this day, the ‘staff’ for the Old Order Amish Caregiver program consists of only the Caregiver Advisor. Due to the culturally sensitive nature of this community, the Caregiver Advisor was required to meet with all Amish Bishops in the numerous church districts to be interviewed and approved. Currently, this Caregiver Advisor is still the only English person accepted to come into the Amish community to facilitate this program

Partners

Again, due to the beliefs of the Old Order Amish, the program does not partner with other agencies that are perceived as “Government.” Amish beliefs do not allow them to accept assistance from state or federal government entities. The Caregiver Advisor has been working closely, however, with the Alzheimer’s Association (as an Outreach Ambassador) to develop training seminars designed specifically for the Amish community.

Outreach

Due to their wish for complete privacy and the closeness of this community, outreach is done 100% by word of mouth throughout the Amish people. If the Bishops (or current Amish client) know of a caregiver in need of

the program, they will contact the Caregiver Advisor directly and ask her to call on that individual in their home. The Caregiver Advisor honors their commitment to privacy. Thus, this method of outreach has worked extremely well and has been key in gaining (and keeping) the trust of the Amish people.

Diversity

The Old Order Amish program is strictly limited to only their community. However, recently, the Caregiver Advisor has been specifically addressing and reaching out to the Amish men who care for their wives. Initially met with some reluctance, more Amish men are now attending support groups and opening up about their caregiving issues. Progress is slow due to the patriarchal nature of this society, but is showing great promise as shown in the statement of one Amish man, “*I never knew I had many feelings to share, it makes me feel better.*”

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A Space of Beauty Journaling Program

Southern Caregiver Resource Center
San Diego, California



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

Background & History

Southern Caregiver Resource Center (SCRC) is a private, nonprofit organization that helps families and caregivers by providing services that are inclusive of all issues related to caring for adults with chronic and disabling conditions and/or advanced age. SCRC’s services are provided at no cost to clients and eligibility for services is based on circumstances inherent to a client’s caregiving situation, not on income or insurance factors. Currently, SCRC receives funding from multiple sources including the CA Department of Mental Health; Aging and Independence Services, County of San Diego; Behavioral Health Services, County of San Diego; private foundations and donations from businesses and individual donors.

The mission of SCRC is to help families and communities master the challenges of caring for adults through cost-effective and prevention-oriented programs and services that address the emotional, physical, and financial needs of family caregivers. SCRC specializes in understanding and working with caregivers of frail, older adults or adults with brain impairments such as Alzheimer’s disease, stroke, Parkinson’s disease, and acquired brain injury.

SCRC is always looking at the feasibility of implementing innovative programs in the communities it serves. In 2004, SCRC endeavored to take an uplifting, new approach to reducing the risk factors associated with caregiving, such as emotional and physical isolation, loss of self-esteem, anger, fear, and guilt. At that time, SCRC initiated a Caregiver-to-Caregiver Network where former caregivers volunteered to serve as “buddies” to current caregivers/clients. Staff quickly learned that volunteers had a desire to help clients in a variety of ways so, with input from volunteers, SCRC started several *walk and talk support groups* and the

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unique journaling program called *A Space of Beauty*. Research supports the value of journaling and it has long been used as a tool in the mental health disciplines. With the assistance of volunteers, several of whom were professional artists, SCRC developed the idea of creating caregiver journals that were customized to each particular caregiver with the thought that these journals would be cherished, used and more meaningful than generic journals that are readily available. Each custom journal was designed with unique prompts to help family caregivers find their voice by providing a safe place to jot down worries, passions, hopes, and new ideas. SCRC also created a class called *Steer With Your Pencil*, that was designed to get caregivers started with their journaling and teach some of the benefits of this activity.

Program Goals

The primary goals of the *A Space of Beauty* program are to allow caregivers a way to refocus their attention on themselves and to create an organized structure through which former caregivers can become involved in efforts to support current caregivers. Through journaling in particular, specific issues may surface that can be dealt with in an environment of safety, thus enabling caregivers to feel less stress and tension in their caregiving role. In addition, SCRC's experience with operating caregiver support groups and literature on mutual aid/peer support has clearly illustrated the many benefits people in challenging circumstances receive from learning and associating with those who have been in a similar situation. Hence, SCRC's use of volunteer artists in the program who have been caregivers was an important consideration. Although staff did not have specific statistical goals in mind when implementing this program, they did plan on evaluating participants' experience in and perceived benefits of the program in order to determine its usefulness and justification for continued inclusion in SCRC's mix of services.

Program Description

Specific steps were taken to develop and implement the *A Space of Beauty* program, most of which were recurrent once the program was up and running, such as recruiting volunteers and connecting with caregivers. Following is a summary of the most pertinent components of the *A Space of Beauty* program:

■ **Find volunteer artists.** Most of the artists are also former caregivers who have first-hand knowledge of the caregiving journey.

■ **Connect with caregivers.** Prior to receiving a journal, caregivers must first complete a formal assessment with one of SCRC's Family Consultants (Master's level clinical staff). The assessment is the first step in becoming a client of SCRC and getting access to our full range of support services. The Family Consultants then develop a Care Plan specific to each client, detailing recommended actions/services based on their specific needs. Clients who are interested in and who might benefit from receiving a journal through the *A Space of Beauty* program are referred to the Director of the Caregiver-to-Caregiver Network (the *A Space of Beauty* program's director). The Director of the Caregiver-to-Caregiver Network connects with referred clients and conducts an in-depth, one-on-one interview with them to gather specific information to incorporate into their unique/customized journal. Questions asked and topics discussed include:

- What are their favorite colors, flowers or gemstone?
- What refreshes their spirit?
- 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 are often 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)?
- If you allow yourself to think about their future, even for a moment, what are some of their hopes and dreams?"

■ **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, a favorite quote, or something related to the person they are caring for (the care receiver). Profiles are typically made available for review by available artists as a group when approximately 10 profiles are ready.

■ **Conduct Workshops.** 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.

■ **Hold Tea Party.** Journals are presented to caregivers at a “Tea Party.” The artists and caregivers attend the Tea Party where each caregiver recipient is presented with his or her unique journal.

■ **“Steer With Your Pencil” class is taught.** The Program 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.

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, staff is able to address the diversity that exists among the caregivers served by this program.

Timeline

Planning and implementation for the *A Space of Beauty* program took five months from inception to startup. Development of the program structure, finding the volunteer artists, identifying caregivers and developing the questions to ask to create the profiles

took approximately two months (out of the five month implementation time period). Interviewing a group of ten caregivers and developing their individual profiles takes approximately one month; hosting workshops where the artists select a profile, gathering supplies and creating the journals takes approximately six weeks; planning and hosting the Tea Party where caregivers receive their completed journal takes approximately two weeks. Based on this timeline, once the program has been established it takes approximately three months to complete one session of caregiver journals, including hosting artist workshops and a *Tea Party*.

Financial Issues

The funding requirements—starting up and maintaining the *A Space of Beauty* program at SCRC— included the following costs:

- One full-time Program Director: approximately \$50,000 per year
- Supplies (office supplies, art supplies, printing/ materials, food for events): approximately \$10,000 to \$20,000 per year

The program was initially funded as part of a grant SCRC receives through the CA Department of Mental Health. Unfortunately, the Caregiver-to-Caregiver Network (of which the *A Space of Beauty* program was a part) was eliminated in 2009 due to SCRC receiving a budget cut of over 70% to the funds received from the CA Department of Mental Health. Even though the Caregiver-to-Caregiver Network was eliminated, SCRC was able to keep a more limited version of the *A Space of Beauty* program in operation as a result of the desire of the program’s volunteer artists’ willingness to continue the service. As of 2011, SCRC does not have a Program Director specifically for the *A Space of Beauty* program. SCRC’s clinical staff and volunteer artists work together to keep the program going. Clinical staff has clients complete journal profiles and then forward them to our group of artists. The artists then manage the process of creating smaller batches of journals (usually no more than three at a time), an effort coordinated by the *lead artist*. Once journals are completed, they are delivered to the appropriate clinical staff at SCRC for distribution to clients. SCRC does not have the staffing or budget necessary to host *Tea Parties* any longer under this new program structure.

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Staffing

Now that the program is unfunded, volunteers and clinical staff must work together more closely to ensure that services are delivered to clients. The program has oversight by a designated lead volunteer and SCRC's Associate Director. The *A Space of Beauty* program should ideally have a staff member that dedicates some or all of their time to the program. However, with severe budget cuts, SCRC has discovered that this type of program can be run largely by volunteers, provided some oversight is provided (e.g., lead volunteer, small portion of hosting Agency's management staff time, etc.). With SCRC's current staffing arrangement, they can no longer serve the number of clients they used to serve, but clients most interested and in need of a journal are still able to be served.

Partners

The primary program partners are volunteer artists from the community. These individuals were chosen because of their artistic ability and, for those who are also former caregivers, for their knowledge of what it means to be a caregiver. Due to the changed program structure and decreased level of volunteer management/recruitment, the number of program artists has decreased, but there is still a core group of artists dedicated to the program due to their personal/professional interest in the innovative services provided and impact made with clients.

Outreach

As the *A Space of Beauty* program is part of SCRC's comprehensive mix of caregiver support services, outreach methods are the same for all programs. SCRC primarily uses its Director of Education and Outreach to market services to caregivers in their service area. Staff participates in health fairs, conducts services orientations/presentations with community groups, provides free community trainings to groups of caregivers and professionals, makes use of an Agency newsletter, uses the website to market services and events, contributes to community publications, and fosters productive partnerships with other community-based organizations.

Diversity

Diversity issues are identified through the assessment process. Diversity among service recipients is then

addressed within specific programs as appropriate. In the *A Space of Beauty* program, diversity is addressed by the volunteer artists during their review of client profiles and conversations with SCRC clinical staff.

Challenges and Barriers

Beyond the obvious challenge of having to revise the program's structure after significant State budget cuts, the following issues have been encountered:

- 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 accepts this as part of the process. In addition, 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.
- 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, including pins created in the form of a journal and embellished with beads and hand-made thank you cards.

Program Evaluation

The program has been evaluated via a survey distributed to clients. Survey results were very favorable.

Lessons Learned

One lesson learned is that in working with artists, while a creative and free flowing experience may be desired, the structure and expectations of the program need to be defined explicitly each time a new session of journals

begins. Many times artists work together 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 (and/or lead volunteer) 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.

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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 were 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 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.

Program 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 caregivers' 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.

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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" 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:

- A qualified Home Educator who possesses a thorough knowledge 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.
- Development of the funding proposal for the program (approximately 15 hours).
- Presentation of the proposal to the agency Board of Directors to approve the program and funding

(approximately 1 hour).

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

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.

Partners

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

Challenges & 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 AFSGB programs. 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 formally 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 from an initial Home Educator visit.

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 professionals. It is vital for the Home Educator to be someone who does not take rejection personally and can bounce back easily from disappointing first contact.

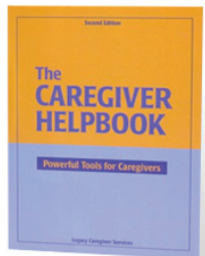
The greatest trap is for the Home Educator to feel as though they are the only one who can provide this service to the caregivers. It places undue stress on the Home Educator, fosters an unhealthy dependence on the Home Educator by the caregivers who frequently see the Home Educator as their personal 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.

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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 three 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 eight years.

Program 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 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

Powerful Tools for Caregivers 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. PTC is a national program sustained by extensive

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collaborations with community-based organizations. As of 2007, the program has reached more than 15,000 family caregivers in over 20 states.

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, and relaxation exercises. Caregivers also receive *The Caregiver Helpbook*, a supplemental guide written especially for the course. This book is available in English and Spanish. Since the program's inception, over 50,000 copies of *The Caregiver Helpbook* have been distributed. A 90-minute six-week series and an on-line version of the program have been developed.

The six-week PTC class has been shown to have a significant positive impact on caregiver health for a diverse group of caregivers including spousal/partner caregivers, adult children and other family caregivers in a variety of settings, including those living in rural and ethnic minority communities. Data from class participant evaluations indicates: significant improvement in self-care behaviors, including exercise and use of relaxation techniques; increased ability to manage difficult emotions, including reduced anger, guilt, and depression; increased self-efficacy in coping with caregiving demands; and increased use of community services.

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.

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 staff 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 & 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 many) has assisted with attracting caregivers to the full six-week series.

When conducting the three-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 from 2000 to 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, staff was extraordinarily successful. In their outreach, staff emphasized Powerful Tools for Caregiving as 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.

Program Evaluation

In the years since the program began, a great deal of research, evaluation and revision has been done to ensure its continued value and success. The six-week PTC class 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/partners, caregivers at differing stages in their caregiving role, living situations, financial and educational backgrounds. Data from class participant evaluations indicates the PTC program improves:

- Self-Care Behaviors: increased exercise, use of relaxation techniques and medical check-ups.
- Management of Emotions: reduced guilt, anger, and depression.
- Self-efficacy: increased confidence in coping with caregiving demands.
- Use of Community Resources: increased utilization of community services.

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/

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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 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, as well as 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 or publicity materials 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 staff 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 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 the reach underserved was reaffirmed and over time has proven to be fruitful for the population served.

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Family Caregiver Project

The House of Justice—Bet Tzedek Legal Services
Los Angeles, California



One of the nation's premier caregiver legal aid programs, Family Caregiver Project offers pioneering educational trainings and clinics to low-income disabled adults, caregivers, and professionals throughout Los Angeles County promoting knowledge about advance planning and protecting seniors' full and equal access to rights and justice.

Anges County promoting knowledge about advance planning and protecting seniors' full and equal access to rights and justice.

Background & History

Bet Tzedek's Family Caregiver Project, begun in 1992, provides legal counseling, advice and representation to adults who are providing in-home care for a family member afflicted with Alzheimer's disease, dementia, or other debilitating illness. Its Family Caregiver staff supports caregivers and care recipients by providing information, advice and counsel, and direct legal representation. Educational presentations in Spanish, English and Asian-Pacific Islander languages are made throughout Los Angeles to a variety of audiences, including health-care professionals, social workers, and caregivers. The Family Caregiver Project operates under Bet Tzedek's Elder Rights Unit, one of six units that make up the organizational structure of the agency.

The idea for the Family Caregiver Project (FCP) began when Bet Tzedek joined a consortium of social services agencies known as 'El Portal,' which was organized and administered by the Alzheimer's Association and funded by the Health Services Resource Administration as a federal demonstration project. El Portal created a network of agencies providing aid to low income, Spanish speaking families in East Los Angeles who were caring for a family member suffering from Alzheimer's disease. When federal funding ceased in 1998, alternative funding was secured from the State Bar of California Equal Access Partnership Fund (EAF) was used to create the project. Specifically, EAF enabled Bet Tzedek to hire a full-time attorney to serve first as our Dementia Care Legal Specialist (and now as the attorney-in-charge of the Family Caregiver Project) and a paralegal dedicated to caregiver issues.

FCP has expanded over the years beyond its roots of

working with El Portal and now serves as the legal services partner to several coalitions (including Asian Pacific Islander Dementia Care Network and The West-Central Dementia Care Network) as well as providing direct services through Bet Tzedek clinics, outreach to Senior Centers, and intake line. In 2009, with support from the UniHealth Foundation, an expansion was launched known as the 'Caregiver Training Coalition.' Bet Tzedek convened this county-wide coalition of agencies providing services to caregivers and their care recipients.

Bet Tzedek Legal Services (BTLS) was founded in 1974 and provides direct legal representation, advice and counsel, outreach and advocacy, to uniquely vulnerable and isolated communities, elderly, refugee, and disabled residents of Los Angeles County, all at no charge.

Program Goals

Bet Tzedek's Family Caregiver Project has met its initial goals, continues to grow it and increase the array of services provided and the number of people impacted. The project continues to:

- Empower low-income, frail adults and their caregivers with information they need to attain protections, denied benefits, and services. Success is measured by the number of cases opened, advice and counsel provided, presentations made, and number of court cases.
- Address the legal needs of caregivers in low income communities by reducing barriers of language, culture, and transportation. Success is tracked by the number of presentations made, the number of people who attend the sessions, and the number of *Caregiver Companion* guidebooks distributed (a 93 page, plain language guidebook in English and in Spanish supported though funding by Amgen in 2010).
- Increase the capacity of community agencies to identify and address the needs of caregivers including making helpful referrals

Bet Tzedek built the Caregiver Training Coalition (CTC), a thriving and growing network of caregiving professionals who come together to learn, share, and enhance client services which now includes 25 partner agencies. These agencies represent key public, private, and non-profit organizations serving the caregiving

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community, including the Department of Mental Health, City Department of Aging, County Department of Aging, the Public Guardian, Adult Protective Services, Elder Abuse Forensic Center, the Los Angeles Superior Courts, the Alzheimer's Association, Jewish Family Services, and Little Tokyo Service Center.

- Build coalitions to advocate on behalf of the unmet needs of caregivers and their isolated care recipients
- Serve as a model for other communities regarding identifying and meeting the legal needs of the growing number of caregivers and their families.

The Family Caregiver Project, along with the Caregiver Training Coalition and the publication of *The Caregiver Companion*, has been recognized by several local and national organizations. Numerous articles have been written and conference presentations have been made by Janet Morris, the director of the Family Caregiver Project at Bet Tzedek Legal Services. The agency is known for its expertise in the area of caregiver's rights and consulted often by members of the legal community. Highlights include travel to Tel Aviv, Israel and to a World Conference on Adult Guardianship in Yokohama, Japan to share the model.

Bet Tzedek identifies and respond to emerging needs (new program reaching out to caregivers of aging adults with developmental disabilities). The attorneys in the Family Caregiver Project continue to identify needs and develop programs to serve disenfranchised members of the community. A new project is now being launched to conduct outreach and education to caregivers of aging adults with developmental disabilities (DD). Thanks to medical advances, DD adults are now living into old age and their family caregivers reach a time when they can no longer care for them due to their own health and aging issues. There is great need for legal protections and planning for the long term care of both the caregiver and the DD adult.

Program Description

Bet Tzedek's Family Caregiver Project is one of only a few programs nationwide that is dedicated to helping family caregivers obtain resources to provide care in their own homes and, in doing so, to avoid costly and impersonal institutional alternatives such as nursing homes. The activities focus upon reaching caregivers within traditionally underserved communities, first within the Latino community, through the El Portal

Project and, more recently, the African-American and Asian-Pacific Islander communities.

The Family Caregiver Project provides direct legal information, advice and counsel, and representation to caregivers and their families. The project also educates both professionals and caregivers, providing access to a wide array of educational materials, legal counseling, and other services in areas related to caregiver support.

The project components are:

- **Workshops or Presentations:** Free, multi-lingual workshops educate, connect, and empower low-income caregivers each year to protect their rights. At community centers and neighborhoods throughout Los Angeles, staff provide plain language, easy-to-understand explanations of legal rights and protections.
- **Trainings:** These innovative trainings are for professionals and agencies that provide services to caregivers.
- **Publications:** Released in June 2007 and updated in 2010, *The Caregiver Companion* is the only resource of its kind in California and is available in English and Spanish. This 93 page, comprehensive manual addresses the most frequently encountered problems and issues surrounding the complex laws and regulations governing caregiving.
- **Clinics:** Empowering caregivers with the tools they need to address basic legal issues on their own, topics include *Advanced Healthcare Directives* and *Elder Law Clinic at the Court*.
- **Outreach:** Bet Tzedek attorneys and paralegals visit approximately 33 community centers throughout of Los Angeles County, ensuring that caregivers and their families have access to a wide array of educational materials, legal counseling, and other services in areas related to caregiver support.

Timeline

The Family Caregiver Project has evolved over the last 19 years along as Bet Tzedek's programs and services have grown and expanded. The project grew out of Bet Tzedek dedication and response to the needs of low income seniors in Greater Los Angeles.

Financial Issues

The support of several important foundations has allowed the program to continue and to expand over the years. Unfortunately, the current weak economy has made the funding for the ongoing services of the caregivers project more difficult to secure. The fundraising efforts of the agency's CEO and board members are focusing on obtaining support from major individual donors for the ongoing services of the Family Caregiver Project. Reduction in state funding have reduced the pass through of Alzheimer's Association (AA) funds to our local AA, reducing funds to our project and also resulting in fewer available alternatives (Medi-Cal, IHSS, Adult Day Health Care) for our clients to keep them in the community.

Staffing

The Family Caregiver Project is a part of the Elder Rights Unit at Bet Tzedek. There is a managing attorney and a project director overseeing the activities of the project. Bet Tzedek also has an overall managing attorney responsible for over sight of the agency's programs. The project has grown significantly. Originally the staff was one full time attorney and one paralegal. Today there are 3 full time attorneys (of which one is the director of the project), 2 paralegals, one social worker, and support staff assigned to the Family Caregiver Project. In addition, *pro bono* partners and law student volunteers leverage the work of the team exponentially.

Partners

The Caregiver Training Coalition included 10 organizations in 2009, its first year and now the coalition has expanded to 25 agencies.

Outreach

Each of the project staff conduct education and outreach programs. In the first seven months of 2011, over 100 presentations have been made to professionals and community groups, reaching almost 5000 people. Caregivers with legal issues have an opportunity to set a one-on-one appointment at the end of the presentation. Referrals from caregivers also come into Bet Tzedek from partner organizations.

Diversity

Several of the partner agencies focus on diverse populations (e.g., Chinatown Service Center, Little Tokyo Service Center). There is great sensitivity to the barriers to service that exist in low-income underserved areas of Los Angeles County. The project staff is bilingual Spanish speakers and other language resources are readily available. In addition, the services of translators are often called upon. Cultural barriers are broken down by meeting clients in their communities at locations that are familiar to them (e.g. schools, senior centers). In the last year, a new collaboration has been forged with the L.A. Gay and Lesbian Center though which a Bet Tzedek attorney conducts intake at the regularly scheduled Thursday night clinics at the Center. Outreach to isolated communities is part of the core mission of the organization.

Challenges and Barriers

The greatest challenge has been maintaining adequate staffing levels to respond to the needs of the clients. Providing quality legal information, advice and counsel, and representation requires significant staff time for each client. Often legal affairs have deadlines on eviction or court dates that demand timely responses. A heavy client load and time sensitive issues often results in a fast paced working environment and long working days. Every effort is being made to leverage the project with *pro bono* partners and volunteers. Funding is being sought through major gifts and foundation support to maintain the current level of service and avoid cut backs or layoffs.

Program Evaluation

The Center for Non-Profit Management in Los Angeles conducted a full evaluation of the Caregiver Training Coalition project collecting data during the first half of 2010. More information about this evaluation can be obtained by contacting Janet Morris at Bet Tzedek.

Lessons Learned

Bet Tzedek found that building a coalition of partners who are interested in serving the needs of caregivers was an invaluable foundation for the project. It provided an opportunity for colleagues to build relationships which fostered better referrals for the clients. Having professional relationships with other social service agencies helps members of the staff to make meaningful

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referrals for issues we cannot address as a legal services provider.

The agency also learned that the needs of the caregiver community are great and as the overall population ages these needs are growing. There are many low income families struggling to pay for food, medicine, and other necessities who benefit from emotional support, accurate information, and access to benefits to which they are entitled.

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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

The Alzheimer's Caregiver Series was developed by an interdisciplinary team at Montana State University Extension in response to an Extension Agent and a community request. Montana is the fourth largest in land mass in the nation with fewer than one million residents. Most of the state has 6.2 persons per square mile and therefore 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 communities. In the Extension unit of Family and Consumer Sciences, MSU has four specialists covering the areas of Family & Human Development, Family Finance, Housing and Environmental Health, and Food and Nutrition.

The MSU Extension Service worked 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.

Program Goals

The goal of the Alzheimer's Caregiver Series was 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 our state. Success was 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, MSU Extension developed the five-week Alzheimer’s Caregiving Series. The first series was offered in the fall of 2005 in northeast Montana. Since the inception of the series, 292 caregivers have been served. Seventy-three program toolkits have been disseminated. One webinar was presented to Extension faculty in Kansas and Nebraska who were interested in implementing the program in these states.

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 rural 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. 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 home.

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.

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.

Timeline

The first series took approximately six months to plan. Development of the toolkit took 10-12 months to plan. However, program developers used some material that had already been developed by the specialists and adapted it for the toolkit, thus reducing the amount of work and time needed to complete the project.

Financial Issues

Funding for the first series was a collaborative effort with a \$3,000 MSU Extension Director’s mini grant, a commitment of \$200 from each of the four Family and Consumer Science Specialist’s operations budgets, and county budget commitments. The total budget for the first series presented in northeastern Montana was \$4,800. Additionally, in-kind contributions of brochures and other materials from the Alzheimer’s Association Montana Chapter were provided, and local in-kind contributions of space to hold the series and refreshments were provided in the counties. Funding to develop the “toolkit” came from the National Alliance for Family Caregiver Award.

Staffing

MSU Extension has a web-based system for County Agents and Specialists to plan work on an annual basis. This program is maintained on the Family & Human Development Specialist’s Plan of Work. County Agents can go to the plan and learn about the program and sign on to offer it. All County Agents who use the program have the Alzheimer’s Toolkit in their offices for use in their counties. At this time, the Housing and Environmental Specialist’s office handles any requests for purchase of the toolkit.

Originally the program was developed and implemented by the four MSU Family & Consumer Science

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Specialists. In addition one support staff person was used to manage the budget for the project. Now that the program is offered via a “toolkit” and one support staff person takes orders and mails out the kits.

Partners

Originally, the primary partners were MSU Extension Family and Consumer Science Specialists, County Extension Agents, and the Alzheimer’s Association Montana Chapter with additional collaboration with the Montana Department of Public Health and Human Services Office on Aging and local hospital and long-term care facilities. Since this project was implemented, the Alzheimer’s Association Montana Chapter has seen a reduction in staff as a grant that helped to fund an outreach director ended. At this time the program is available in the form of a “toolkit” that can be used by Extension agents and health educators. The “toolkit” is available at www.alzheimerstoolkit.info. The formal partnership is no longer in effect; however, the program maintains contact with the state Office on Aging and the Alzheimer’s Association Montana Chapter as needed.

Outreach

County-level Extension Agents continually assess the constituents in their counties to determine programming needs.

Diversity

The program was offered to all interested caregivers. Several Certified Nursing Assistants and other health-care professionals have attend the training and found it to be valuable for their personal and professional lives. Program staff did not receive any feedback that the program was not beneficial for various cultural or ethnic groups. In Montana the majority of the population is White (non-Hispanic) with the largest minority population (approximately 6%) being Native American.

Challenges & Barriers

Originally the plan was to offer the series one time in northeastern Montana. That series served more than 80 caregivers. Then requests came in from other areas of the State and subsequently series was offered in the northwest, southwest, and southeast portion of the State. Each Extension Specialist spent approximately one week travelling to the small communities in each

area of the State to present his/her program for the series. This was costly. To address that challenge the Extension Specialists worked together to develop a “toolkit” containing the presentations, factsheets, and supplemental materials so that County Agents and health educators could offer the program locally without the Extension Specialists travelling. This toolkit was then advertised on-line for sale and each County Agent received a copy. Information on the toolkit is available at www.alzheimerstoolkit.info.

Program Evaluation

During the first series an extensive evaluation was conducted. The evaluation of the project was based on the logic model of evaluation assessing short-term, medium-term, and longer-term outcomes. Data were gathered at three different points of time. Short-term outcomes were measured through a pencil and paper evaluation given at the end of each presentation (there were five sessions, once per week). A telephone interview 6 weeks after the end of the series with a random sample of the participants assessed medium-term outcomes. A telephone interview conducted five months after the end of the series with another 89% of randomly selected participants revealed that 89% agreed or definitely agreed that they had increased self-confidence in caregiving and 100% were better prepared for their role as a caregiver. Based on the workshop, 78% had a better understanding of the food and nutritional needs of people with Alzheimer’s and 43% had sought more information and started exploring legal guardianship or conservatorship for their loved one. Home modifications for the health and safety of the individual with Alzheimer’s were started by 57% of those contacted.

Anecdotal and observational data also provided valuable information. One woman, who believed she may have early stages of Alzheimer’s, attended because she wanted to learn more. Another woman who had not been able to be out of her husband’s sight because of the disease started using respite care. Her husband had been resistant to going to a daycare facility but by the third session he was comfortable with the arrangement. This allowed his wife to receive needed respite.

A journal article was published in the *Journal of Extension* on the evaluation process and results which can be viewed at <http://www.joe.org/joe/2008february/a1p.shtml>. The evaluation also revealed that participants

were interested in continued educational programming on caregiving which has led them to offer the *Powerful Tools for Caregivers* program throughout the state.

Lessons Learned

MSU did not realize how popular this program would be when the first series was implemented. Families in rural Montana were very interested in learning about caregiving for loved ones with Alzheimer's disease. First, MSU learned that it was important to take the program out to the people in small communities. Originally a one day-long session was to be held covering all five lessons in the program in a larger community in the northeast. However, caregivers could not leave their loved ones for an entire day and travel – even as little as 30 miles. This was good advice as MSU reached more caregivers by travelling to them. The first series took MSU to six communities within a week to present the programs. Second, they learned the importance of providing care for the care recipient so that the caregiver could attend the program. This was accomplished in a variety of ways but primarily by the County Agent collaborating with a local health care facility. Third, collaboration with other community entities was important for the success of the project. Finally, MSU learned that the County Agents ability to develop relationships with the caregivers was crucial to their continued attendance. Participants in some areas continued to meet for coffee as a group following the end of the series.

Contact

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

MinnesotaHelp Network
Rochester, Minnesota

www.MinnesotaHelp.info[®]

“Connecting People of All Ages to Community Help”

Long-term Care Choices was developed to assist older Minnesotans and their caregivers to age well, live well, plan well and care well.

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.

Our 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 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

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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

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 allows the site to customize 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 the Long-Term Care decision tool. 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
- 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. Currently, users report satisfaction with ease of use and how comprehensive the web site is. Web metrics have been tracked since August 2006.

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.

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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 service 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. The focus group participants articulated what was missing: a one-to-one approach that connects caregivers 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 identified as a coach, a guide, a navigator for the caregiving journey. Eldercare Partners Caregiver Services was launched in 2002.

Program Goals

Through the Eldercare Partners 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. This assessment includes 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. The program currently uses a wellness scale, which is believed to be more strengths-focused.

The caregiver and family consultant works 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 results in reflection and getting to the heart of the matter; and requesting or inviting the caregiver to stretch beyond self-imposed limits. 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 is 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.

Although caregivers of all ages have used this service, it seems to especially resonate with adult children caregivers—baby boomers—who are typically working caregivers and appreciate the need to maintain balance among their many personal and professional roles.

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.

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. Dr. Lum used 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. Dr. Lum measured caregiver burden, expected duration of caregiving, ability to provide care, and access to support services. This evaluation found that Eldercare Partners Caregiver Services does reduce caregiving burden. The evaluation revealed the following:

- The baseline 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.

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- 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% 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.

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 staff has not pursued coaching credentialing, this too is an option. A number of coaching training programs and professional associations could serve as a resource to emerging programs.

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Family Support Services

Mountain Empire Older Citizens, Inc.
Big Stone Gap, Virginia



MEOC's Program for Family Caregivers 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 and for caregivers to have access to an infrastructure of support services to meet their needs.

Background & History

Mountain Empire Older Citizens, Inc. (MEOC), serves as the Area Agency on Aging, Public and Specialized Transportation Provider, Children's Advocacy Center and Aging and Disabilities Resources Center for the Central Appalachian jurisdictions of Lee, Wise, Scott counties and the City of Norton located in the far southwestern tip of Virginia. Bordered by Tennessee and Kentucky, the mountainous region served by MEOC is closer to eight other state capitals than it is to its own state capital of Richmond and a person traveling to Richmond from Lee county would travel 465 miles (930 miles round-trip) to attend state trainings, meetings and conferences.

Established in 1974 with a small \$12,500 planning grant, MEOC presently operates a \$12.8 million budget using over 100 different funding sources to provide 40 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: the development and maintenance 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 in the late 1980's which still functions today providing valuable information and keeping MEOC grounded in service and on mission.

As is the case with all MEOC's programs and services, the programs under the umbrella of Family Support Services are developed and implemented in response to the expressed needs of those served. Family caregivers, through focus groups, support groups, surveys and public hearings shared and continue to share their stories and their needs. MEOC began placing major emphasis on services for family caregivers in the early 1980's in response to a series of public hearings held across our region attended by many family caregivers who spoke eloquently and movingly of their personal situations and the needs of their loved ones for whom they provided total care.

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, MEOC has placed a major emphasis on services that support, encourage, empower and educate family caregivers. Since the program's inception, thousands and thousands of family caregivers have received assistance. Presently, an average of 270 caregivers receives respite assistance through MEOC's initiative annually with numbers growing. MEOC has a dementia specific component to its services resulting in dementia responsive services for individuals with dementia, related disorders and their caregivers.

MEOC's Family Caregivers Support Services goals continue to be met. Monthly reports on all programs and activities are maintained electronically, submitted to appropriate funding sources, as well as MEOC's Board of Directors and MEOC Advisory Councils and are available on both a monthly and year to date basis. Evaluations are completed by caregivers for all programs on an annual basis.

Program Description

The caregiver support infrastructure developed by MEOC presently includes eight community group

respite centers (Brookdale Model), an in-home respite program, an overnight and emergency respite program, two adult day health care centers, care coordination, four caregiver support groups (including two Alzheimer's groups one of which is an online Alzheimer's support group, one family caregivers support group and one relative caregiver group for Grandparents raising Grandchildren), a Family Caregiver Resource and Support Lending Library and caregiver education programs, including an evidence-based Chronic Disease Self-Management Program.

Pharmacy assistance, personal care services, homemaker services, personal emergency response systems, legal services, transportation, emergency services, assistance with insurance issues, home-delivered meals, home repairs and home safety program are additional services available to assist caregivers.

In 2008, MEOC opened a Program of All-Inclusive Care for the Elderly (PACE), one of the first such rural programs in the nation. It is a person centered holistic care model for the frailest and sickest centered on an Inter-Disciplinary Team which emphasizes, among other concerns, the support of family caregivers of those enrolled in PACE.

MEOC is placing increased emphasis on assisting person with cancer and their families and offers concrete services, educational materials and patient navigation services through its Mountain Laurel Cancer Support and Resource Center.

There is a growing epidemic of relative caregivers raising young children in our region and, as a result, demand on MEOC's KinCare Program is increasing. The KinCare Program provides assistance with back to school supplies, monthly family social activities, case management, transportation, holidays for kids and a support group mentioned earlier.

Each year MEOC serves over 2,800 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. MEOC's annual budget for Family Caregiver Support Services is \$1.6 million (excluding transit).

The uniqueness of MEOC's Program for Family Caregivers is that it is not just a single service, but it is a comprehensive set of services intentionally

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developed over the years for the purpose of providing a one stop entity for caregivers and 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 include a goal of 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 local, state and federal resources, to address needs as expressed by the local community.

Timeline

The program began in 1974 and currently offers human services including an adult day health care program, online support groups, family caregiver resource lending library and overnight emergency respite services.

Financial Issues

Mountain Empire Older Citizens has been faced, over the past five years, with shrinking dollars and increased need. MEOC has continued through challenging economic times to remain committed to providing the services which caregivers deem the most needed.

Stagnant federal and state budgets have not kept pace with inflation and increased need and reductions, particularly in state appropriations, have impacted our programs in the form of extensive waiting lists for critical services such as in home respite, home delivered meals and homemaker services. The program has recently been impacted by a reduction in the maximum number of respite hours for those receiving Medicaid waived community based services and reduction in reimbursement rates for providers of community-based services such as adult day health care and personal care services.

MEOC has had to be creative while making some very tough decisions in responding to these financial challenges. MEOC has redirected its Older Americans

Act Title III E funds through the National Family Caregiver Support Program to address respite homemaker waiting lists, provide personal care services and supplement Care Coordination funding for family caregivers. It has also redirected its Title III Older Americans Act funds to basic services designed to reduce unnecessary institutionalization such as personal care, homemaker and care coordination while reducing funds to other less critical services

As MEOC has lost administrative staff through attrition, those positions have not been filled as a way to prevent major reductions in services. MEOC has reduced its number of community group respite centers from ten to eight and reduced the weekly number of hours of homemaker services for family caregivers by one hour as a means to stay within budget. MEOC has been able to sustain its state respite grant funding and surprisingly received a slight increase in funding this past year.

Mountain Empire PACE has presented a new and important revenue stream to MEOC and persons choosing to transition to that model of community based care receive the full array of caregiver support services based on an individualized care plan developed by the Inter-Disciplinary team, the PACE participant and the family. This is a capitated health care plan funded primarily by Medicare and Medicaid.

United Way funding has been helpful in providing funds to supplement MEOC's efforts in meeting the needs of family caregivers for adult day health care and in-home respite services.

Increased local fundraising efforts have played a major role in sustaining MEOC's programs. The local community raises over \$500,000 annually through private donations and community fundraisers to support the work of MEOC. The Masonic Home of Virginia is an important partner of MEOC whose assistance and support has increased. They pay MEOC to provide community based services to specific older Masons living at home cared for by their families.

MEOC has put a greater emphasis on recruiting volunteers the past several years to assist in MEOC's core services. This has resulted in costs savings as volunteers now deliver all services in MEOC's large Liquid Nutrition program. Volunteer drivers are now recruited and trained to assist increased demands on MEOC's Transit Program which is under financial

strain because of rising fuel costs. MEOC's strong partnership with the faith community continues to grow with increased donations and volunteers to assist those served by MEOC, particularly in the area of home repairs and home modifications to make homes accessible.

Staffing

The Director of the Department of Family Support Services reports directly to the Executive Director and is a member of MEOC's Management Team. She is responsible for all services within that department. Each service within Family Support Services has oversight by a specific program director. Each program director provides the day to day supervision for respite aides, personal care aides, adult day health care aides, homemaker and other staff.

The MEOC Management Team comprised of all Department Directors, MEOC's Executive Director, MEOC's Deputy Director and MEOC's Chief Financial Officer, meets every two weeks to discuss program/ agency issues, review budget issues and concerns and to make sure that all of the management team is kept updated and is on the same page.

MEOC has a fifty member Advisory Committee which meets quarterly and an eight member Board of Directors that meets every other month. In addition, MEOC has a ten member Caregiver Services Advisory Committee that meets quarterly that provides invaluable advice, support and direction specifically for the Department of Family Support Services

The programs included in the Department of Family Support Services are managed by Bachelor's and Master's level supervisors. Family Support Services also has a total of six Registered Nurses serving in the capacities of personal care supervisors and adult day health care directors. There is a Director of the Department of Family Support Services who reports directly to MEOC's Executive Director and who also serves on MEOC's Management team.

The PACE program of MEOC has an interdisciplinary team which includes a medical doctor, two RN clinical supervisors, two family nurse practitioners, a registered dietitian, a physical therapist, an occupational therapist and two MSWs.

Support staff members are individuals who have completed a minimum of a forty hour Virginia Department of Medical Assistance Services approved Personal Care Aide training curriculum. MEOC also employs a good number of aides who are state certified nursing assistants. Currently, approximately 185 employees are involved in direct client care. Staffing has increased yearly in these services.

Partners

MEOC regards partnering as a key to all its efforts. Since its inception in 1974, MEOC has emphasized the importance of developing close working relationships with other agencies, organizations, the faith community and local businesses and civic organizations. Key partners involved in MEOC's family caregiving efforts are:

- Area hospitals
- Parish Nursing Program
- Center for Independent Living
- AARP
- Community Health Clinics
- Virginia Senior Navigator
- Churches and People of Faith
- Veterans Administration
- Masonic Home of Virginia
- Virginia Caregiver Coalition- MEOC is a founding member.
- University of Virginia Health Sciences Library Outreach at the College of Wise
- Mountain Empire Community College
- And many other partners.

A key to the success of MEOC's programs for family caregivers is MEOC's 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.

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

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quality training for caregivers and professionals in the region because MEOC involved 20 other organizations and associations who each provide a small amount of funding which, when pooled, allows sufficient funds to host 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.

Outreach

Referrals are received from a variety of sources with the majority coming from the partners referenced in the previous section, families and self-referrals. All referrals are handled through MEOC's Care Coordination Department. A care coordinator does a home visit with the individual and with the assistance and involvement of the family completes a total assessment on the person needing services. Following the assessment, a care of plan is developed with and signed by the person which authorizes the MEOC Care Coordinator to locate and put in place all available services, benefits and supports to allow him/her to remain at home in his/her own communities. The Care Coordinator accesses all the services offered by MEOC as well as all appropriate and needed services available from other community resources. By working with families and addressing needs, the Care Coordinator locates services, explains services, applies for services, sees that the services are put in place and monitors the developed care plan.

MEOC brochures describing its services and giving contact information are available for people stopping by the MEOC offices and are also placed at literally hundreds of places throughout the service area.

The staff of MEOC also does presentations as part of its outreach activities to churches, civic organizations and at other health and human services organizations and is a frequent presence at local health fairs and community events sharing the MEOC story.

MEOC also informs the community of services available through MEOC by utilizing space on Mountain Empire Transit vehicles. The fleet includes sixty-three vehicles from large buses to smaller vans which travel all around

our three county service area on a daily basis.

Most recently, Mountain Empire PACE has used television commercials to inform the public of this program. MEOC's website is www.meoc.org MEOC is also on Facebook.

Diversity

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

Challenges & Barriers

The largest challenges encountered over the past decades of providing services are:

1. Federal and state budget reductions
2. Stagnant federal and state budgets
3. Rising cost of gasoline and other transportation costs
4. Increasing numbers of persons in need placed on long waiting lists for services due to insufficient funding to meet the region's needs

MEOC has placed a new emphasis on local fundraising efforts and, as always, the local communities have responded to the call. Our local churches, civic organizations and individuals always come through when the times are the tightest. We have combined some of our programs, including our community group respite sites, in an effort to save money.

Volunteer recruitment has played a major role in helping to maximize our funds. New volunteers are now serving as volunteer drivers to assist in meeting those critical transit needs which we encounter almost daily. Our geographic location is a barrier for some of our elderly friends and neighbors and volunteer drivers provide trips to medical and other appointments while providing specialized support to the passenger. Several volunteers also currently deliver our liquid nutritional supplements to those with a cancer diagnosis and their caregiver. This represents a substantial savings to MEOC. MEOC is constantly seeking opportunities to locate new funding sources. At any given time, it is not unusual for MEOC Management to be working on proposals to new potential funding sources.

Program Evaluation

MEOC has evolved over the past 37 years from an area agency on aging solely offering basic Older Americans Act services to a multi-funded organization providing a wide array of services to caregivers and older individuals. These programs have been built over the years by: listening 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 to what extent 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 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. MEOC

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 ideas and learn about concerns.

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. The turnout was tremendous 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 an environment of trust that is so important to MEOC’s success.

Subsequent well-attended public hearings have provided valuable information in guiding MEOC to be caregiver responsive in its service initiatives.

Whenever MEOC undertakes any initiative, it is done in partnership with others. MEOC’s advice is to choose partners wisely and involve those organizations that share similar values, 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, those 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 a variety of national, state and local funding sources to provide the array of caregiver services it offers. A diverse funding base is a critical component for sustainability. Do not put all your eggs in one basket. Also, do not isolate your funding sources in various departments. It takes more than one entity to support our work. Experts today talk of “braiding,” intertwining, “quilting,” and layering, of

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funding. Though MEOC was not familiar with those terms in the past when developing our support services for family caregivers, the terms are aptly descriptive of MEOC's past and present practices. The key is always to be searching for potential investors with mutual interests.

MEOC, through its efforts, is known as an advocate for the needs of caregivers and continues to work in concert with others to make this issue an important part of the public discussion on local, state and national levels. MEOC always includes the voices and faces of caregivers in all situations and never presumes to speak as the expert. Caregivers are the experts and MEOC recognizes and honors that fact. Establishing and maintaining the trust of caregivers is essential. Without it, caregiving programs will flounder and never really take hold.

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Strengthening the Delivery of Family Caregiver Education through Partnership Program

Bethany Home, Inc.
Waupaca, Wisconsin

This program enables a caregiver to take care of himself or herself while they are caring for another.

Background & History

Bethany Home Inc. acquired the Wisconsin Alliance for Family Caregiving in January of 2009, keeping the caregiving curriculum training coordination of Powerful Tools for Caregivers and Caregiving Relationships. University of Wisconsin-Extension Madison holds the curriculum Bethany Outreach Services coordinates the class leader trainings and keeps track of the classes being led in communities throughout Wisconsin.

Goals

The goals of the program(s) are to enable a caregiver to take care of himself or herself while they are caring for another. The program gives caregivers the techniques of better communication not only with family members but also with healthcare professionals and addresses issues of stress, anxiety, and depression. The program also ensures that caregivers know that they are not alone and they can ask for help.

Program Description

As of January 2009, over 1,000 Class Leaders in 27 states and Canada have been trained to deliver Powerful Tools for Caregivers (PTC) in community-based settings. Class leaders have taught PTC to more than 15,000 caregivers.

Caregivers at differing stages in their caregiving role and living situations have all benefited from PTC. Data from class participant evaluations indicate:

- Significant improvement in behaviors: increased exercise, use of relaxation techniques and health self-care
- Improved emotions, including reduced anger, guilt, and depression
- Increased confidence in coping with caregiving demands
- Increased community service use.

Timeline

Since 2009 class leaders have been trained in nine counties; seven counties still need trained class leaders. It is still the goal to train class leaders in those areas.

Financial Issues

Since 2009 funding was received from grants and donations from various sources, including Helen Bader Foundation, Fox Valley Community Foundations and church and private sector donations. Funding becomes a challenge in the far reaches of the state if turnover of trained leaders occurs after 2011. Ongoing efforts will be underway to help prevent this situation from becoming an issue ever again because of collaborations with the Board of Aging and Disability Resources (BADR) and the Greater Wisconsin Agency on Aging Resources (GWAAR). Continued support of the statewide caregiver network through quarterly telephone/web conferences and 1:1 or individual county/collaboration assistance will be sought for in 2012 and thereafter, but the framework of how this support continues will be determined by the end of this particular 'Statewide Expansion Project' in conversations with BADR and the GWAAR.

Staffing

The primary responsibilities of staff is providing class leader training and support to class leaders conducting classes in their communities. Each class provided to a community by a class leader is required to conduct survey of the class and submit survey results. The director of outreach programs has changed since February 2011; outreach programs are under the direction of the Social Services Director of Bethany Home, Inc. in Waupaca, Wisconsin.

Partners

Program partners are UW-Extension Madison (curriculum) and GWAAR, (class leaders and Master Trainers). The newest addition is WIHA that supports efforts of prevention and caregiving. The program also has local partnerships with Hospital Health and Wellness department, physicians and clinics.

Outreach

The program provides outreach through a network of caregiver coalition members, faith organizations,

healthcare providers and the Aging and Disability Resource Center.

Diversity

The programs are offered keeping in mind the diversity in the community. Based on research evaluation, significant outcomes are documented at six 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 Help Book* have been distributed.

Program Evaluation

This program has been designed to support caregivers of adults with a chronic condition in a way that enhances their well-being as they care for others. It was carefully designed, pilot-tested, evaluated, and refined to ensure program quality and evidence-based outcomes. The foundation of the program is based on extensive research by Dr. Kate Lorig and associates at Stanford University's Patient Education Research Center and uses concepts of adult learning and self-efficacy. In order to sustain the high quality of this program, Class Leaders and Master Trainers conducting *Powerful Tools for Caregivers* programs and training must adhere to the principles and requirements of the program.

Lessons Learned

The most important lesson the program has learned is to follow the proven protocol and make changes as needed to fit with changing needs.

Contact

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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,” 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.

Program 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 caregivers of stroke “victors,” 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 to develop the program.

Information is typed directly onto the computer templates as each section is reviewed with the caregiver. 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 on to 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, exercise programs, church/ temple services, and others.
4. **Phone Book:** This section includes all emergency contacts and physician information, immediate family contact information, professional advisors, such as therapists, general phone book (friends, distant family, etc.).
5. **Hurricane/Disaster Preparations:** Needs are listed and plans are outlined.
6. **Wishes/Advanced Directives:** This section contains copies of the following documents: Living Will, DNR, Health Care Surrogate, Power of Attorney, Funeral Arrangements, and any other related documents that the victor and caregiver want included.

7. Designs: This section includes additional information that each caregiver wants included in the Manual that may have been overlooked and/or identified as important to the caregiver and not included in the other sections of the Manual.

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 one-on-one communication between the caregiver and the Caregiver Education volunteer assures that individual needs among the diverse members of the stroke community are met. Caregiver Education volunteers are trained to respect individual differences and to assure that each Caregiver Manual meets the needs of the individual caregiver and “victor”.

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 program 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.

Partners

- Stroke of Hope Caregiver Education volunteers
- Caregivers
- Stroke victors

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 Stroke of Hope organization. Effectiveness/impact has best been demonstrated through the on-going requests from other individuals or groups for assistance in developing their Caregiver Manual.

Contact

Stroke of Hope Club, Inc.
www.strokeofhope.org

Asian American Dementia Care Network

Alzheimer’s Association of Los Angeles, Riverside, and San Bernardino Counties
Los Angeles, California

alzheimer’s  association™

This effective inter-organization collaborative model extends to multiple Asian American 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, California Southland Chapter 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.

In response to significant growth of Los Angeles’ Asian older adult population, the Alzheimer’s Association has targeted several Asian communities for the development of caregiver services for low income and working class families. In July 2000, the initial Asian Pacific Islander Dementia Care Network built upon inter-organizational collaboration to develop and provide dementia care services in under-served ethnic communities. The Asian Pacific Islander Dementia Care Network targeted 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 received one-to-one assistance with direct caregiver support activities that have included respite care funds; support groups (six new groups established and conducted in Japanese, Chinese, Vietnamese and Korean); and caregiver training. In addition, over 8,000 members of the general public benefited from linguistically matched education about memory loss and Alzheimer’s disease.

Over the past few years, the need developed to expand the Asian Pacific Islander Dementia Care Network to serve additional ethnic groups, especially the area’s large elderly Filipino population, and to expand services for low to

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moderate income members of the Japanese and Chinese communities. Starting in 2009, the Asian Pacific Islander Dementia Care Network (APIDCN) received two grants from private foundations to continue the work in these communities. By building on community strengths and overcoming cultural barriers to help-seeking behavior, the Asian Pacific Islander Dementia Care Network enhanced the current infrastructure of caregiver supports for the Chinese and Japanese communities and expanded to the Filipino community.

Program Goals

The overall goals of a Dementia Care Network (DCN) are to:

- Establish linkages and build trust between local community organizations and the Alzheimer's Association;
- Facilitate the coordination of existing services in the target area and to identify gaps and barriers to service delivery.
- Identify agencies in the targeted communities that can provide families and caregivers with culturally appropriate and dementia knowledgeable care.
- Evaluate existing translated information, develop linguistically and culturally appropriate materials and disseminate them to the community through provider networks.

Program Description

The Asian Pacific Islander Dementia Care Network is an inter-organizational community-based collaborative model established to provide dementia care services to an ethnic community. The model brings together nonprofit human services providers, program consumers, community representatives and government entities. It has enhanced dementia care service capacity and contributed to alleviating the psychological, emotional, and financial stress associated with caregiving.

In general, the Asian Pacific Islander Dementia Care Network addresses cultural barriers by:

- Increasing awareness of the disease through outreach activities and the ethnic media
- Decreasing stigma associated with Alzheimer's disease
- Offering Care Advocates, bilingual and bicultural

paraprofessionals

- Facilitating access to existing services through a trained Care Advocate
- Creating culturally and linguistically appropriate literature
- Providing support groups in the language of choice
- Providing respite funds and legal services to family caregivers
- Facilitating program development and expansion

Timeline

Most of the agencies involved formally in the APIDCN have worked together in the community for years prior to the project and have developed a sense of trust of the other agency. During the start-up phase of the APIDCN, a significant amount of time is directed to identifying and training the Care Advocates, who need to learn about dementia, caregiving issues and existing services prior to recruiting clients into the project. The constant community presence for a period of years is necessary to develop trust and credibility. In Los Angeles, our experience is that three to five years is the minimum time to develop services, assist clients and institutionalize the dementia knowledge within the partner agencies and service providers.

Financial Issues

The level of funding has varied from the initial Dementia Care Network to the current APIDCN. Typically, services and staffing are added to the project as the funding level increases. The most recent grant award was \$750,000 over three years for the APIDCN and represents one of the larger Dementia Care Networks in any ethnic community. This funding supports three Care Advocates, a full time staff member at the Alzheimer's Association, respite funds, development and translation of education materials and a large-scale evaluation component.

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. Providing respite funds have attracted some families to the project initially, who then benefits from the support and education.

Staffing

The Alzheimer's Association is the lead agency for the APIDCN. In addition to providing administrative oversight for the project, the Association is responsible for contract management, technical assistance, caregiver and staff education programs, media outreach to the targeted populations and coordination of project partners. Quarterly Steering Committee meetings are held with all project partners in attendance to discuss overall issues, and monthly Care Advocate meetings are held by the Care Advocate Mentor to resolve difficult client issues and update project activities. Frequent email and phone correspondence are also conducted.

The APIDCN has a project manager at the Alzheimer's Association, and each partner agency hosts a Care Advocate and a clinical supervisor. The number of staff and amount of time devoted to the project depends on the funding level available through grants or if agencies are able to absorb the costs of the positions within their own general fund. As the Dementia Care Network evolves, additional staff is trained to expand the number of dementia knowledgeable service providers within each agency.

Partners

The strength of the APIDCN is the collaboration among agencies. These partnerships often develop years before a formal project which allows the agencies develop a relationship based on trust. Some APIDCN agencies have worked informally with the Alzheimer's Association for over twenty years while others have more recently become partners. The purpose of the partnerships is the collective ability to develop and offer culturally competent programs. The result includes our partner agencies institutionalizing their newly acquired dementia capacity in the services they offer to the community.

Outreach

One of the major goals of the Dementia Care Network is to evaluate existing translated information, develop linguistically and culturally appropriate materials, and disseminate them to the community through provider networks. Older immigrant populations, where many of the Chinese and Japanese caregivers are identified, tend to speak their native languages. The Filipino community is primarily English speaking, but many also use a mix of Tagalog and English. Agencies distribute Alzheimer's Association education materials in English with some materials available in Chinese and Japanese. Additionally,

presenting information in the language of the participants has been much more effective than relying on translators. The project's outreach efforts include local community groups, churches, temples, political leaders, physician offices, senior housing, caregiver conferences, and informal neighborhood networks.

Diversity

The Dementia Care Network Model was developed specifically for implementation in underserved and ethnically diverse communities. To date, the Dementia Care Network model has been used the aforementioned Asian and Pacific Islander communities as well as with the African American and Latino communities.

Challenges & Barriers

In the APIDCN, the greatest challenge has been overcoming issues of stigma about dementia and Alzheimer's disease. Strategies to decrease the stigma have included educating the public that this is a brain disease and not a mental health problem. Also, the ethnic media has played an important role by covering stories that de-stigmatize the disease and highlight services through the APIDCN.

The issue of caregiver utilizing respite services has been challenging. To address financial barriers, APIDCN provides funds for clients to pay for expenses such as in-home care and adult day care programs. Some issues identified as to why respite use is lower than expected include paid caregivers who do not speak the client's language, feelings of fear and mistrust of having a stranger in the home, and lack of cultural understanding about the benefits of respite. Due to feedback from the caregivers, the use of respite funds was expanded to also include assistance for home modifications and services.

Program Evaluation

The initial program evaluation focused on consumer satisfaction and service utilization rates prior, during and after the intervention. Although simple and straightforward, feedback was very positive and the caregivers increased their use of formal services after enrolling in the project. In the past two years, private funding has permitted a more formal and comprehensive evaluation of the model and its impact on the caregivers. Specifically, the areas of caregiver burden, satisfaction, and depression will be analyzed.

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The data collection period will conclude in 2012 with a data analysis report in early 2013.

Lessons Learned

The lessons learned from this project have remained the same since the initial DCN 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. Our 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 our services.
- Mentoring care advocates. These individuals are the heart of the project and the greatest advocates for the families. Our experience is 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 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.

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Supporting Caregivers through Technology

Family Caregivers Alliance
San Francisco, California



FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

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, 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.

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

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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 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. 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 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. 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 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 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, trouble shoot 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 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

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how Washington State is now considering introducing legislation to include caregiver assessment within their Medicaid program modeled after the state of Idaho's legislation 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.

Contact

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AARP
ALS Association
Alzheimer's Association
Alzheimer's Foundation of America
American Academy of Home Care Physicians
American Geriatrics Society: Foundation for Health in Aging
American Occupational Therapy Association
American Psychological Association
American Red Cross
American Society on Aging
CareOptionsOnLine (*NavGateTechnologies*)
Caring.com
Center for Advancing Health
Centers for Medicare and Medicaid Services
Children of Aging Parents
Easter Seals
Eli Lilly & Co.
Family Support Center (*Caregivers of NJ*)
Genworth Financial
GlaxoSmithKline
Hamacher Resource Group, LLC
Healthcare Leadership Council
Home Instead, Inc.
Johnson & Johnson
LeadingAge (*formerly American Association of Homes and Services for the Aging*)
LifeCare, Inc.
Lighthouse International
Lupus Foundation of America, Inc.
Mather LifeWays
MetLife Mature Market Institute
n4a (*National Association of Area Agencies on Aging*)
National Association of Chain Drug Stores Foundation
National Association of Professional Geriatric Care Managers
National Association of Social Workers
National Center on Caregiving/Family Caregiver Alliance
National Council on Aging
National Hospice and Palliative Care Organization
National Multiple Sclerosis Society
Older Women's League
Paraprofessional Healthcare Institute
Parkinson's Disease Foundation
Pfizer
Sanofi-Aventis
UnitedHealth Group
U.S. Department of Veterans Affairs:
Verizon
Well Spouse Association
Women's Institute for a Secure Retirement



Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations. 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 provide important societal and financial contributions toward maintaining the well-being of those they care for, 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. To learn more about the National Alliance for Caregiving, visit www.caregiving.org.

MetLife Foundation

MetLife Foundation was established in 1976 by MetLife to carry on its longstanding 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.