

January 2006

Alzheimer's Disease Demonstration Grants to States Program: Colorado

Final Report

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COLORADO**

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Contract No. GS-10F-009L MOBIS
Delivery Order No. HHSP233200400143U

January 2006

This project was funded by the Administration on Aging under contract no. GS-10F-0097L MOBIS, Delivery Order No. HHSP233200400143U. The statements contained in this report are solely those of the authors and do not necessarily reflect the views or policies of the Administration on Aging or RTI International. RTI assumes responsibility for the accuracy and completeness of the information contained in this report. The authors would like to thank the ADDGS Grant staff, other state officials, providers, consumers, researchers, educators and others who gave so generously of their time to provide information about Grant activities.

*RTI International is a trade name of Research Triangle Institute.

EXECUTIVE SUMMARY

The Alzheimer's Disease Demonstration Grant to Colorado was awarded to the State Board of Agriculture, acting by and through Colorado State University (referred to in this document as Colorado State University or the University). The University, in collaboration with the Colorado Alzheimer's Association and with support from the Aging and Adult Services Division of the Department of Human Services and the Area Agencies on Aging, administers the Grant.

The Grant funds two primary initiatives as part of this evidence-based project: the Savvy Caregiver Program and the Virginia Behr Respite Grants. The Savvy Caregiver training is an evidence-based dementia care training program. It was originally developed, tested, and evaluated as a psycho-educational curriculum for caregivers by the Department of Family Practice and Community Health at the University of Minnesota and Metro Lakes Chapter of the Alzheimer's Association. The program is designed to train family and professional caregivers in the basic knowledge, skills, and attitudes needed to mediate the challenges of caring for a family member with Alzheimer's disease and to be an effective caregiver (Ostwald et al., 1999; Hepburn et al., 2001, 2003). The Virginia Behr Respite Grants provide up to \$1,000 per year per family for direct supportive services. The funds may be spent at the discretion of the family for in-home services, adult day care, or short stays in a nursing home. The secondary purpose of the respite grants is to encourage family members to continue to use supportive services in the future and providers to offer adult day services where they had not done so previously.

The overall goal of the FY 2002-2005 ADDGS Grant was to increase access to supportive services in rural areas of the state, with special sensitivity to the bilingual Hispanic population. The project was designed to:

- Increase the availability of supportive services in the state's rural areas by training family and professional care providers in the Savvy Caregiver Program.
- Promote rural families' use of available programs/services through outreach by the Alzheimer's Association and other providers.
- Coordinate rural access to supportive services.
- Participate in a task force with other providers of Alzheimer's disease services. The intention of the task force was to make recommendations for future statewide Alzheimer's disease initiatives.

Because the state of Colorado is so large and much of the state is rural, the ADDGS Grant staff needed to design and implement a program that specifically addressed geographic isolation (Starns, Karner, and Montgomery, 2002). The Savvy Caregiver Program was a very appealing training program to address that issue. The training follows a "train the trainer" curriculum and is designed to create local knowledge and resources for isolated communities.

ADDGS Grant staff have been successful in overcoming practical barriers by remaining flexible in their approach to implementing the Savvy Caregiver Program. Because of the large

distances involved in traveling to the training and the time involved in the training itself, the format and duration of the trainings were modified from 6 weeks to a 1-, 2-, or 3-day format while the content of the curriculum remained unchanged.

A key reason for the success of the ADDGS Grant was the way in which it built service capacity and developed local resources to support this effort. Capacity was built from both the individual and service provider perspectives. Initially, individuals were resistant to using respite services, which research has shown diminishes the caregiver's feelings of stress, burden, and depression (Mittelman et al., 1996). However, the availability of \$1,000 direct service grants made these supportive services more appealing to family caregivers. Because the caregivers experienced the desired benefits, including decreased rates of depression corresponding to an increased participation in support groups and services, the appeal of the respite services increased. Grant staff acknowledged that the money did not go far; however, it was not designed to do so. After respite grants funds were exhausted, many individuals realized the benefit of the program and were more inclined to either purchase respite services out of pocket or use Medicaid benefits if they qualified. Providers also viewed the availability of direct service grants as an incentive to offer respite services. Having an adult day consultant available to support adult day care program start-up served as an additional motivation for providers.

Among the lessons to be learned from the Colorado ADDGS Grant program are that effective educational interventions for family caregivers and infrastructure development in rural areas require:

- An understanding of the cultural and philosophical background of potential participants.
- Flexibility and willingness to adapt the evidence-based model to meet local community needs.
- The development of a supportive infrastructure to promote the creation of adult day care programs.
- The development and ongoing refinement of evidence-based evaluation tools to monitor program performance and assess effectiveness over time.

Although it is too soon to determine the long-term effects of the FY 2002-2005 ADDGS Grant, previous evidence-based research suggests that the Savvy Caregiver training and respite grants will give caregivers the means to increase their skills, knowledge, and confidence, resulting in decreased stress and better care.

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INTRODUCTION: OVERVIEW OF ADDGS PROGRAM AND CASE STUDIES

Alzheimer's disease is a devastating degenerative disease that causes memory loss, challenging behavior problems and severe functional limitations. A person with late stage Alzheimer's disease requires constant supervision, support and hands-on care. While many persons with Alzheimer's disease are admitted to nursing homes, the majority of people with the disease live in the community, where their families provide most of the care.

To improve services to persons with Alzheimer's disease, Congress established the Alzheimer's Disease Demonstration Grants to States (ADDGS) program, which is administered by the U.S. Administration on Aging. The program's mission is to "expand the availability of diagnostic and support services for persons with Alzheimer's disease, their families, and their caregivers, as well as to improve the responsiveness of the home and community-based care system to persons with dementia. The program focuses on serving hard to reach and underserved people with Alzheimer's disease or related disorders (ADRDs)" (U.S. Administration on Aging, no date).

This paper describes one of five case studies conducted by the ADDGS National Resource Center in 2005 on the activities of selected state programs. The goals of the case studies are to:

- Document "promising practices."
- Identify policy issues in the program and in providing services to people with Alzheimer's disease and their families.
- Identify strategies for accomplishing program goals.
- Identify implementation barriers and ways of overcoming them.
- Assess how selected sites are addressing the goals of the ADDGS program.

Two of the themes of the case studies are *evidence-based practices and replication of promising practices*. In both approaches, the key question is how to adapt key elements of an existing or previous intervention into a different community setting for which the initiative was not originally designed. In these case studies:

- *Evidence-based practice* refers to using services and programs that are based on rigorous research methods and findings. An example would be the use of the National Institute on Aging-funded Resource for Enhancing Alzheimer's Caregiver Health (REACH) research to identify what services should be provided and how or the use by the Colorado ADDGS Grantee of the Savvy Caregiver Program developed and evaluated by the University of Minnesota. Another example would be ADDGS Grantees building research and evaluation activities into the project so that the initiatives' impact can be determined objectively.
- *Replicating promising practices* refers to implementing initiatives that have not been rigorously evaluated but seem worthy of duplicating in other settings. For example,

the California ADDGS Grantee applied the concepts of the Hispanic-focused El Portal model to other ethnic groups, even though the original project had not been evaluated using sophisticated research methods.

To illuminate the issues involving evidence-based practice, Colorado and California were selected for case studies.¹ Colorado was selected as a case study site because the program is administering an evidence-based program modeled after the Savvy Caregiver Program for rural caregivers developed by the University of Minnesota. In this project, the Alzheimer's Association Colorado Chapter conducts the training and gathers the data, and Colorado State University conducts the analysis and disseminates the findings.

The overall goal of the FY 2002-2005 ADDGS Grant was to increase access to supportive services in rural areas of the state, with special sensitivity to the Hispanic population. **Exhibit 1** lists the 2002-2005 ADDGS objectives.

Exhibit 1. Main Components of Colorado ADDGS Grant, FY 2002-2005

- In partnership with the Alzheimer's Association Colorado Chapter, the Grantee increased the availability of supportive services in the state's rural areas by training family and professional care providers in the Savvy Caregiver Program.
- Grant activities promoted rural families' use of available services through outreach conducted by the Alzheimer's Association and other providers.
- The Grantee participated in a task force with other providers of Alzheimer's disease services. The intention of the task force was to make recommendations for future statewide Alzheimer's disease initiatives.

On July 11, 2005, the University and Alzheimer's Association Colorado Chapter received notice of a second ADDGS award to the Board of Governors of the Colorado State University System (formerly the State Board of Agriculture). Consistent with the Governor's designation, the new project is administered through Colorado State University's Tri-Ethnic Center for Prevention Research in collaboration with the Alzheimer's Association Colorado Chapter. For the purpose of this report, the Grantee will be referred to as Colorado State University or the University. The new award is designed to build on the prior project by continuing the Savvy Caregiver training, offering approximately 500 respite grants, and providing follow-up services to the rural population in the state. Additional services will be provided through targeted caregiver training programs and related services for underserved minority populations and developmentally disabled adults coping with dementia (Colorado Alzheimer's Project, 2005a).

Information for this case study was gathered by reviewing administrative files at the U.S. Administration on Aging and Web sites, and by conducting an in-person site visit in July 2005 in Fort Collins and Denver, Colorado. As part of the site visit, RTI staff interviewed ADDGS staff,

¹The theme of the other case studies is systems change. ADDGS programs in Maine, North Carolina, and Oklahoma were selected to illustrate those issues.

state officials, research experts, providers, and consumer groups. Based on the review of administrative files and Web sites and the interviews conducted during the site visit, RTI compiled lessons learned to develop an effective educational intervention for rural caregivers. **Exhibit 2** lists the principal findings from the Colorado case study.

Exhibit 2. Principal Findings from the Colorado Case Study

The Colorado ADDGS Grant program learned that having an effective educational intervention for rural family caregiver requires:

- An understanding of the cultural background of potential participants.
- Flexibility and willingness to adapt the evidence-based model to meet local community needs.
- The development of a supportive infrastructure to promote the creation of adult day care programs.
- The development and ongoing refinement of evidence-based evaluation tools to monitor program performance and assess effectiveness over time.

BACKGROUND ON THE COLORADO ADDGS GRANTEE AND PRIME CONTRACTOR

General Background on ADDGS Grantee and Contractor

The Colorado ADDGS project was awarded in 2002 to the State Board of Agriculture acting by and through Colorado State University's Center on Aging. The Grant was administered collaboratively by the University and the Alzheimer's Association Colorado Chapter. The overall purpose of the Center on Aging is to integrate the education, research, and outreach activities of the University as they relate to aging. A consistent theme of the Center's work is the prevention of excess disability and optimization of quality of life for older persons (Colorado Alzheimer's Project, 2002). Combining the mission of the University, the research interests of the Project Director, the reputation of Colorado's Alzheimer's Association and the close working relationship between the Association and the University helped to successfully develop and implement the ADDGS Grant.

The mission of the Alzheimer's Association Colorado Chapter is to diminish the effects of Alzheimer's disease and related disorders by increasing the understanding of dementia and its impact on family and community, providing information and support for those affected, and promoting the advancement of research (Alzheimer's Association Colorado Chapter, 2005). Founded in 1980 as the result of the merger of four area chapters, the Colorado Chapter provides a range of services to Coloradoans with Alzheimer's disease through its seven regional offices.

Description of the 2002-2005 ADDGS Grant Program

The U.S. Administration on Aging awarded Colorado State University a 3-year ADDGS Grant for June 2002 through June 2005. The primary initiatives of the project are:

- Statewide implementation of the evidence-based Savvy Caregiver Program for caregivers and professionals in rural areas.
- Development of consumer-directed respite grants, new support groups, and new adult day programs to increase rural families' use of supportive services.
- Coordination of Alzheimer's disease services and access statewide and dissemination of program impact.

Savvy Caregiver Program

The Savvy Caregiver Program was originally developed, tested, and evaluated as a psycho-educational curriculum for caregivers by the Department of Family Practice and Community Health at the University of Minnesota and the Metro Lakes Chapter of the Alzheimer's Association. The program is designed to train family and professional caregivers in the basic knowledge, skills, and attitudes needed to mitigate the stress and challenges of caring for a family member with Alzheimer's disease and to effectively carry out the caregiving role (Hepburn et al., 2003). Using a "train the trainer" approach, the 12-hour evidence-based Savvy Caregiver Program provides basic knowledge and skills to family members and professional caregivers to increase caregiver skills and confidence, create reliable and accessible networks of

support for caregivers, and increase access to supportive services (Smith and Bell, in press). Because the training is “train the trainer,” professionals and family members can subsequently serve as resources for others in the community. Staff at the Alzheimer’s Association conducted the Savvy Caregiver trainings in rural and underserved areas.

The formal training component consists of approximately 12 hours of sessions that involve teaching various objectives for the caregivers (e.g., acknowledging the disease, developing emotional tolerance, taking control) in addition to providing the participants with a caregiver manual and educational CD (Hepburn et al., 2003). The manual provides a written version of the skill-building information discussed during the trainings. The CD provides additional educational materials, including a cognitive performance estimation procedure² and video clips of experts suggesting interventions for behavioral problems during the various stages of dementia (Scharf, Bell, and Smith, in press).

During the 3-year grant period of the FY 2002-2005, the seven regions of the Alzheimer’s Association Colorado Chapter provided a total of 41 trainings at 36 sites for 282 caregivers. Caregivers learned about the availability of the training through a variety of sources, including Alzheimer’s Association Colorado Chapter newsletters and helpline, the Area Agencies on Aging, state agencies, public service announcements in newspapers, physicians, home health providers, assisted living facilities, and word of mouth. The University conducted the evaluation component of the ADDGS Grant to determine the effects of the training and materials on caregivers.

Use of Supportive Services and Other Caregiver Training

In addition to enhancing the skills and knowledge of Alzheimer’s disease among caregivers, the Savvy Caregiver Program is designed to increase the awareness of family and other providers regarding the need for supportive services and to encourage providers to meet the demand for these services. Families and professionals participating in the Savvy Caregiver trainings and others are informed of the availability of respite care grants up to \$1,000 per family per year. This financial assistance is for direct supportive services available through the ADDGS Grant. Known as the Virginia Behr Respite Grants, these funds can be used for in-home services, adult day care, or short stays in a nursing home. Virginia Behr was a volunteer at the Alzheimer’s Association Colorado Chapter who left an endowment for respite grants; when the federal funds became available, the grants were already known as “Virginia Behr Grants.” The family decides how to use the funds. Individuals receiving services from the state’s Medicaid home- and community-based services waiver are not eligible; otherwise eligibility is nonmeans tested. These funds meet the direct care requirement of the ADDGS Grant and were awarded to 377 participants between 2002 and 2005.

To assist communities interested in establishing adult day programs, an ADDGS Grant-funded consultant worked with communities to determine the viability of developing adult day care programs. By the end of July 2005, eight new adult day programs were established and

²Known as the “toast test,” individuals with Alzheimer’s disease are presented with all the items needed to make toast with butter and jam and asked to complete the task. The level of assistance or redirection required is used to assess the individual’s level of cognitive functioning. Through the Savvy Caregiver training, the caregivers are taught to gauge expectations and interactions based on this level of functioning.

seven more were pending, in part because of the guidance provided by the consultant. Other important factors contributing to the expansion of adult day services have been support from the Centers for Medicare & Medicaid Services-funded Systems Change Real Choice Grant for two of the centers, the interest generated by the Savvy Caregiver trainings and consumer-directed Virginia Behr respite funds, and the local leadership provided by the Area Agencies on Aging and Alzheimer's Association area coordinators (Colorado Alzheimer's Project, 2005a).

Partly because of the interest generated by the Savvy Caregiver trainings throughout the state, the Alzheimer's Association Colorado Chapter was able to establish Alzheimer support groups in six rural communities during the 2002-2005 time period. In addition, the Association developed six groups, known as "Memory Cafés," to provide nonstigmatizing recreational and support programs to caregivers and their loved ones in a neutral setting. Building on the social model of care developed in Kansas to provide peer support to people disinclined to attend formal "support groups," the Memory Cafés offered caregivers the opportunity to socialize, share experiences in the presence of their relatives, and provide activities for the person with dementia. The activities provided through the Café include dinner (generally a potluck), singing, and dancing. ADDGS Grant funding covered costs associated with the Alzheimer's Association's staff's involvement and travel to and from the site. Generally, Alzheimer's Association staff members obtain donations to cover the expenses associated with renting the space and providing refreshments.

The ADDGS Grant also provided scholarships to support the Alzheimer's Learning Institute. This program, one of several offered by the Alzheimer's Association Colorado Chapter, is designed to provide paid caregivers training on a full range of topics related to caring for a person with Alzheimer's disease, such as communication, behaviors, and teamwork in the dementia care setting. Paid caregivers participating in this training earn a 32-hour certificate in dementia care. Hiring staff with this certification assures facilities and families that the person they hire to provide care has special dementia care training. Over the course of the Grant, scholarships were provided to 116 caregivers to participate in the Alzheimer's Learning Institute.

ADDGS Grant funds also provided 91 scholarships for families to enroll in the Alzheimer's Association Colorado Chapter's Wandering and Safe Return program. This nationally based program teaches family caregivers about the increased need for supervision when a dementing illness impairs judgment and increases disorientation and confusion. The Safe Return program provides assistance when a person with Alzheimer's disease or a related dementia wanders and becomes lost. Safety considerations to protect the person with memory impairment include ways to reduce wandering behavior, first steps to begin a search when a person is missing, a national registry that can be accessed by public safety agencies, and a Safe Return identification bracelet for the person with Alzheimer's disease that includes an 800-number and instructions on who should be contacted when the individual is located.

Coordination of Services, Access, and Dissemination

To coordinate access to services for individuals with Alzheimer's disease and their family members and plan future initiatives, ADDGS Grant staff initiated the formation of a statewide task force. The representatives from state agencies, Area Agencies on Aging, and providers of direct services and health care who served on this committee agreed to meet quarterly to:

- Discuss areas where coordination of services needed to be improved.
- Implement new coordination efforts.
- Incorporate the outcomes of the first two objectives into future initiatives (Colorado Alzheimer's Project, 2002).

However, partly because of severe statewide budget cuts and subsequent efforts to maintain existing programs rather than expand supportive services, the Coordination Task Force met only twice during the third year of the Grant. ADDGS Grant staff did keep Task Force members apprised of their activities.

The Project Director and Alzheimer's Association staff traveled throughout the state and met with community leaders, legislators, service providers, physicians, Area Agency on Aging staff, and caregivers to provide community outreach and educate communities and individuals about ADDGS Grant activities and services. Because of the community connections and the interest generated through research update presentations made by the Project Director, greater numbers of individuals were able to benefit from the Savvy Caregiver trainings, respite funds, and other Grant-sponsored initiatives.

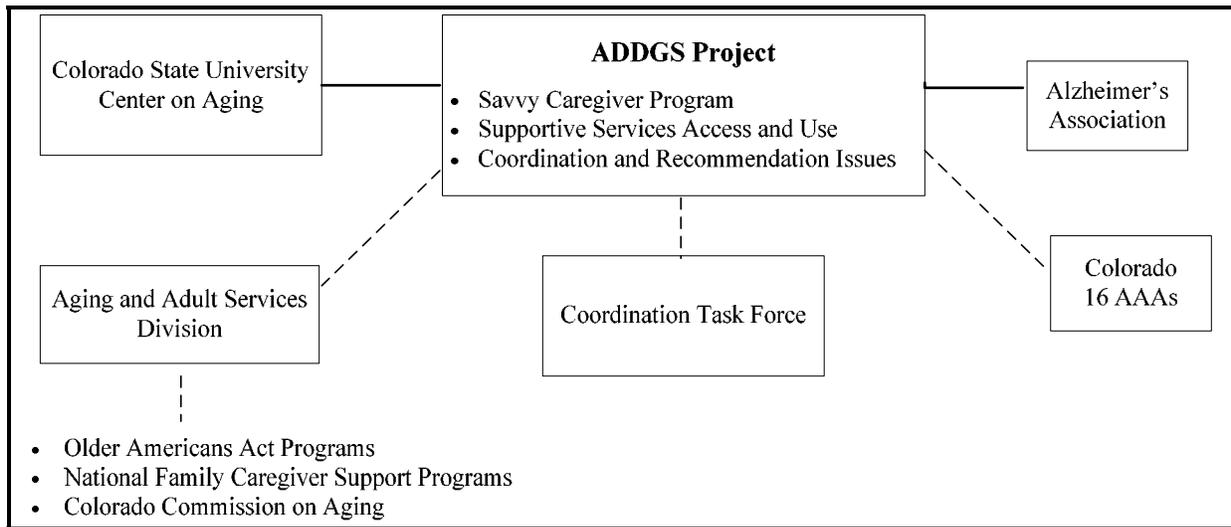
Grantee Partnerships

The Colorado State University Center on Aging and Alzheimer's Association collaborate to implement the activities of the ADDGS Grant. Both organizations work with the Colorado Department of Human Services, Aging and Adult Services Division. The Aging and Adult Services Division is responsible for programs related to the Older Americans Act, adult income and medical support, adult protective services, and the activities of the 16 Area Agencies on Aging in the state. The Area Agencies on Aging house the National Family Caregiver Support program, which is funded by the U.S. Administration on Aging. One of the program staff at the Aging and Adult Services Division is the main point of contact for Grant staff. A program staff member at the Aging and Adult Services Division serves as the liaison between the ADDGS Grant and the Area Agencies on Aging, National Family Caregiver Support Program, and the Colorado Commission on Aging. This Commission serves as the policy advisory committee to the Aging and Adult Services Division; the Grant collaborates with and reports to the commission on a periodic basis.

The Colorado Area Agencies on Aging help identify sites for the Savvy Caregiver trainings, recruit training participants, identify families for dementia-related services, and provide service utilization data.

Exhibit 3 displays the organizations involved in the ADDGS Grant.

Exhibit 3. Partners in the Colorado ADDGS Grant, FY 2002-2005



Source: Colorado Alzheimer's Project (2002).

EVIDENCE-BASED PRACTICES

Background, Selection of Evidence-Based Practices, and Prior Study Findings

The Savvy Caregiver Program is the primary evidence-based practice on which the FY 2002-2005 Grant was based. Additionally, the Colorado ADDGS project evaluated the effectiveness of the award of the respite grants. Individuals identified as having a family member with Alzheimer's disease or professional direct care staff are offered the Savvy Caregiver training; family members are offered up to \$1,000 to pay for respite services. Throughout the ADDGS Grant, 190 individuals participated in the Savvy Caregiver Program, 331 families received the respite grants, and 46 families received both (Colorado Alzheimer's Project, 2005b).

Development and Evaluation of the Savvy Caregiver Program

The Savvy Caregiver Program was modeled after the Minnesota Family Workshop developed by researchers at the University of Minnesota and the Metro Lakes Chapter of the Alzheimer's Association to train family and paid caregivers to manage stress and implement their daily caregiving responsibilities (Hepburn et al., 2003). During the early development of the program, University of Minnesota staff approached the Denver office of the Alzheimer's Association Colorado Chapter about possible replication, and in the fall of 2000, the Association agreed to participate in the field test of the Savvy Caregiver Program. The program creators provided on-site training to the Denver office leadership and telephone consultation to answer questions and solve problems regarding the program's implementation (Hepburn et al., 2003).

The purpose of the pilot evaluation of the Minnesota Family Workshop-based Savvy Caregiver training was to determine whether family caregivers would benefit from a program designed to provide them with the knowledge, skills, and caregiving outlook needed to understand and function effectively in their role (Ostwald et al., 1999; Hepburn et al., 2001). The key study question was "if caregivers learn to view their role as a caregiver from a more clinical, strategic perspective, would feelings of burden and depression be lessened?" The pilot demonstrated that the short training program had positive outcomes for caregivers. The study found that those caregivers who participated in the training, when compared with similar caregivers not receiving the training, had significantly better scores on measures of caregiver outcome, including:

- Depression.
- Burden.
- Reaction to care receiver's behaviors.
- Beliefs about caregiving (Ostwald et al., 1999; Hepburn et al., 2001).

In addition, learning from the training materials, linking the caregiver to community services and supports, and seeing the benefits of the informal cognitive assessment (toast test) lessened the emotional components of providing care and helped caregivers have realistic expectations of the family member with Alzheimer's disease (Ostwald et al., 1999; Hepburn et al., 2001; Hepburn et al., 2003).

Once the Denver staff obtained the results of this initial evaluation, they decided to implement the program statewide in the hope of achieving the same effects. The Alzheimer's Association Colorado Chapter approached state officials from the Aging and Adult Services Division to obtain their support for submitting the initial ADDGS Grant and consulted with the Colorado State University's Center on Aging Director to request that they evaluate this program through the ADDGS Grant.

Study participants consisted of caregivers of persons with Alzheimer's disease living in small cities, towns, or rural areas.³ Caregivers living in larger cities and towns served as the comparison group for the rural areas. Participants were recruited through the seven regional offices of the Alzheimer's Association and through the Area Agencies on Aging; participation was voluntary and free of charge. During the study period, 190 caregivers agreed to complete the client intake form, which formed the basis of the University's ADDGS evaluation. The client intake form, developed by the University of Kansas for the U.S. Administration on Aging-funded study of the ADDGS program, also included questions of relevance to the Savvy Caregiver training, demographic information on the client and caregiver, and scales assessing the memory-impaired person and the caregiver's current mental status (e.g., depression). The questionnaire also inquired about the amount of time the caregiver provided care, employment status, and a self-report measure of overall health (Scharf, Bell, and Smith, in press).

Exhibit 4 provides a summary of the demographic and geographic background of caregivers who participated in the training and responded to the specific sections of the questionnaire.

Results of an evaluation conducted with caregivers 6 months after participating in the Savvy Caregiver training indicate that rural participants who completed surveys and questionnaires before the training and at the 6-month follow-up used the printed material and CD with some frequency following the training, had structured meaningful activities with the person with dementia, reported lower depression scores at follow-up, and increased their use of support groups (Smith and Bell, in press). More specifically, using information from the intake form to compare pre and post variables of depression scores using analysis of variance with repeated measures, university researchers found that the average depression scores decreased between baseline and the 6-month follow-up. When urban/rural subgroup differences were examined, however, the differences in the rural group's depression scores were statistically significant, while the pre and post differences for the urban group were not. Support group use by rural caregivers increased significantly during the 6-month evaluation but not for the urban caregivers (Smith and Bell, in press). The researchers concluded that these findings suggest that "targeting rural communities for caregiver training could result in more use of supportive services, effective caregiving strategies, and improved caregiver well-being, even in low density population areas where supportive services are more difficult to access" (Smith and Bell, in press, p. 2).

³According to U.S. Census definitions, a small city or town has fewer than 50,000 residents and a rural area has fewer than 2,500 people.

Exhibit 4. Demographic and Geographic Information of Savvy Caregivers, FY 2002-2005

Characteristic	Percentage
Age Range	33–101
Gender	(n = 134)
Female	56
Male	14
Unknown	30
Race	(n = 148)
Black/African American	2
American Indian/Alaska Native	1
White	95
Other	2
Ethnicity	(n = 148)
Hispanic or Latin	3
Not Hispanic or Latino	97
Income	(n = 133)
<\$8,000 to \$12,000	15
\$12,000 to \$20,000	13
\$20,000 to \$40,000	26
>\$40,000	39
Unknown	7
Relationship	(n = 144)
Spouse/domestic partner	33
Adult child	55
Other	12
Geographic Location	(n = 159)
Rural/farm	30
Small city	35
Medium city	19
Large city	16

Source: Colorado Alzheimer’s Project, 2005b.

Evaluation of Respite Grants

The hypothesis of the University's evaluation was that increased access to respite services in rural areas will increase use of these services and improve the quality of life for individuals and families dealing with dementia (Colorado Alzheimer's Project, 2002). Based on this premise, the Colorado ADDGS project decided to offer grants of up to \$1,000 to caregiving families to purchase respite for in-home services, adult day care, or short stays in a nursing home. The Alzheimer's Association tracked service utilization, and the University conducted the analysis as part of the evaluation component of this Grant. The University used the same intake form for this program as for the Savvy Caregiver and added a few questions that specifically pertained to the respite grants. During the 6-month follow-up evaluation, no statistically significant effects were found for either the rural or urban caregivers (Smith and Bell, in press). These findings may be attributable to the small sample size given the low numbers of participants early in the Grant.

Challenges in Applying Evidence-Based Practices

The Colorado ADDGS partners, the Alzheimer's Association Colorado Chapter, and Colorado State University have considerable experience and expertise in their respective areas. Even so, numerous challenges had to be overcome to successfully implement the Savvy Caregiver Program across the state of Colorado. Some of the challenges faced by the ADDGS partners were:

- Cultural and philosophical barriers.
- Logistical/geographic barriers.
- Challenges in achieving consistent training.
- Limited availability/use of day care and supportive services.

Cultural, Philosophical, and Language Barriers

Although the Savvy Caregiver Program was offered to individuals of all ethnic/cultural backgrounds, getting a diverse group of individuals to participate in the training sessions proved to be challenging. While approximately 9 percent of the Colorado state population over 60 is Hispanic, only 3 percent to 7 percent of program participants were Hispanic. A barrier to participation was that the program was only offered in English. In addition, traditional Hispanics believe "dementia" means crazy; it is a demeaning term they do not want associated with their loved one. A third barrier to participation was that the Hispanic population strongly believes in taking care of their own family members, so the use of respite services was strongly resisted in traditional households.

Recognizing that the Savvy Caregiver training course was not appealing to the Spanish-speaking population, the staff directing multicultural initiatives at the Alzheimer's Association Colorado Chapter created and pilot-tested two programs specifically designed for the Hispanic population. The programs, *Memory Loss: Is It Normal or Not?* and *Diabetes and Your Brain*, generated interest and involvement by the Hispanic population of caregivers. These 1-hour

presentations can be used at churches or with civic groups and are intended to serve as an introduction to other services provided by the Alzheimer's Association Colorado Chapter. The *Diabetes* presentation documents how diabetes doubles the risk of memory-loss disorders and describes steps a person can take to reduce risk of the disease, which has a high prevalence in the Hispanic population (Beeri et al., 2004; Haan et al., 2003). Both programs have been incorporated into the new FY 2005-2008 ADDGS Grant.

As part of the FY 2005-2008 Grant, to better serve the Hispanic population, two graduate students fluent in Spanish joined the evaluation team at the university. These students can converse with program recipients in the language preferred by the participant.

In addition to the cultural barriers limiting the participation of the Hispanic population, Colorado ADDGS staff had to overcome resistance to using supportive services by families having a "frontier spirit." In particular, ADDGS staff members were surprised by the initial low use of the respite grant funds. These families did not use respite care partly because they preferred to save for a later emergency rather than spend money to buy care for their relative. After Grant staff promoted the project through existing providers of day and in-home care and knowledge spread by word of mouth from families benefiting from the respite grant program, the number of families using the respite services increased.

Logistical/Geographic Barriers

The Savvy Caregiver training was originally designed to be conducted over 6 weeks with 2 hours per session. Because of the distances that the trainers and participants needed to travel and the amount of time involved in traveling and training, the Colorado ADDGS Grant staff condensed the material into a 1-, 2-, or 3- day workshop during consecutive weeks with no significant impact on the training's effectiveness (Scharf, Bell, and Smith, in press). To be responsive to the needs of each regional office, the Alzheimer's Association Colorado Chapter now allows each regional coordinator to select the training format. Factors that have affected the decision to have a 1-, 2-, or 3-day training during consecutive weeks include input from participants and the distance necessary to travel to the training.

Challenges in Achieving Consistent Training

The Alzheimer's Association Colorado Chapter consists of seven regions, each of which has a coordinator who conducts the trainings in his/her respective regions. Some regions also have trained volunteers who also conduct the Savvy Caregiver trainings. To ensure that the program material would be presented consistently across the state, Alzheimer's Association staff created a structure for each session that captured the most important points. While coordinators are given considerable latitude in the additional material to include in the training sessions, they are required to cover the "essential information" during each training session.

GRANT STRATEGIES FOR SYSTEMS AND SUSTAINED CHANGE

Promoting systems and sustained change is a priority for the U.S. Administration on Aging; ADDGS states accomplish system change by implementing activities that result in ongoing modification in state or provider practices, policies, and financing of services for people with Alzheimer's disease. Sustained change or sustainability is achieved through systems change or obtaining other sources of funding.

Leveraging of Resources

To date, the ADDGS Grant has had limited success in leveraging additional funding. The Project Director has established a foundation that funds Alzheimer's research; however, only a small amount of support has been provided. In addition, the Project Director has committed a proportion of his own University-supported discretionary research funds to support the prior and current ADDGS evaluation efforts.

An additional source of funds to support the Alzheimer's Association Colorado Chapter has been the U.S. Administration on Aging's National Family Caregiver Support Program. These funds have been used to support Savvy Caregiver training sessions in urban areas (such as Fort Collins) and general caregiver training sessions in urban areas (including Denver and Colorado Springs).

The Alzheimer's Association Colorado Chapter also has been involved in fund-raising activities to support its overall program activities. Although these efforts have not been used directly to support the ADDGS Grant, they have helped the Alzheimer's Association provide additional caregiver support services to the community at large. Two fund-raising programs that have been most successful are:

- *Memories in the Making.* People with Alzheimer's disease create pictures/paintings to be shown in a juried art show. Framed works are auctioned off after being shown statewide. Individuals pay a fee to attend the juried art show. This event raised several hundreds of thousands of dollars.
- *Memory Walk.* This sponsor-driven fundraiser takes place in several locations across the state. Individuals obtain sponsors to support their walking activity. The walk takes place in 12 sites around the state in rural and urban areas. The money raised each year is pooled and split among the seven regions statewide.

Plans to Sustain ADDGS Grant Activities Once ADDGS Grant Ends

Efforts have been made to sustain the program at the completion of the Colorado ADDGS Grant period. The eight adult day care programs will need to obtain private or Medicaid funding from clients because ADDGS Grant funding was only intended to provide start-up assistance, not to support the programs over time. However, the ADDGS project staff hopes that the Virginia Behr respite grants will serve as an incentive for individuals to use these adult day care programs and other supportive services once these funds are exhausted. These respite grants are designed to show individuals the value and need to obtain care for their relative outside the home. It is too soon to tell whether the respite funds will be used as a catalyst for subsequent

private-pay services once the Grant has ended. Once the current Grant is over, the rural Savvy Caregiver trainings could be financed through either private or state funds and could be conducted by trained volunteers from the local community. However, the ADDGS Project Director does not expect state funds to be available.

Finally, as of May 2005, a tax refund check-off program to benefit the Alzheimer's Association was signed into law. In this type of program, a taxpayer "checks off" a contribution to a specific fund or organization on a state personal income tax form. The funds that are voluntarily provided to the Alzheimer's Association will help maintain at least some of the new services generated by the ADDGS project and expand other Alzheimer's Association initiatives. It is uncertain to what extent the ADDGS Grant will benefit from this new opportunity to obtain public funds to support Alzheimer's Association activities.

CONCLUSION

The FY 2002-2005 Colorado ADDGS has increased access to supportive services for family members caring for loved ones with Alzheimer's disease and other types of dementia in rural parts of the state. Implemented through a collaborative effort with Colorado State University's Center on Aging, the Alzheimer's Association Colorado Chapter, the Area Agencies on Aging, and the State Unit on Aging, the project has been able to provide evidence-based caregiver training and respite services to families, as well as technical expertise to communities interested in establishing adult day services.

The ADDGS Grant program included two central components: the Savvy Caregiver training for rural caregivers and cash respite grants to family caregivers for respite services in communities that lacked supportive services or were resistant to using them. The Savvy Caregiver program was designed to provide family caregivers with the skills, knowledge, and caregiving outlook that would let them care for the person with Alzheimer's disease or dementia more effectively (Ostwald et al., 1999; Hepburn et al., 2003; Scharf, Bell, and Smith, in press). The formal training program includes a classroom-based caregiver psycho-educational curriculum developed by researchers at the University of Minnesota and the Metro Lakes Chapter of the Alzheimer's Association, along with a caregiver training manual and a CD containing a variety of reference documents. Colorado State University evaluated the program's effectiveness and determined that, over time, participation in the Savvy Caregiver Program decreased the rate of depression, increased the average use of services, and increased the participation in support groups.

The second focus of the original ADDGS Grant was to increase caregiver awareness of supportive services in their communities and encourage providers to meet the demand for services in these rural settings. This goal was accomplished by providing up to \$1,000 in respite grants to families to purchase noninstitutional services for in-home respite services, a short stay at a nursing home, or adult day services. These consumer-directed service grants motivated rural providers to consider offering adult day services. ADDGS Grant staff also hired an experienced adult day care consultant to work with providers to develop adult day programs in rural community settings.

Because the state of Colorado is so large and much of the state is rural, the ADDGS Grant staff needed to design and implement a program that addressed isolation from other technical resources, including limited numbers of trained staff (Starns, Karner, and Montgomery, 2002). For these reasons, the Savvy Caregiver Program was a very appealing evidence-based training program for family caregivers. The training follows a "train the trainer" curriculum. It is designed to create local knowledge and resources for isolated communities. All training materials remain with the caregiver for future reference once the classroom component has been completed. As part of the program's evaluation, the University found that even a year after the training, at least some caregivers continued to refer to these materials to compensate for the lack of other technical resources (Smith and Bell, in press).

ADDGS Grant staff have been successful in overcoming practical barriers by remaining flexible in their approach to implementing the Savvy Caregiver Program. Because of the long distances involved in traveling to the training and the time involved in the training itself, the

format and duration of the trainings was modified from 6 weeks to a 1-, 2-, or 3-day format without changing the content of the curriculum.

To build community awareness of Alzheimer's disease and available services, the Project Director at Colorado State University and the Alzheimer's Association staff traveled across the state to speak to service providers, physicians, caregivers, and other members of the community. The topics of the talks included current research findings on Alzheimer's disease and information about the grant initiatives and services.

A key reason for the success of the ADDGS Grant was the way in which the Grant built service capacity and developed local resources to support this effort. Capacity was built from the individual and service provider perspectives. Initially, individuals were resistant to using respite services, which research has shown diminished the feelings of stress, burden, and depression (Mittelman et al., 1996). However, the availability of direct service grants made these supportive services more appealing to family caregivers. Because the caregivers experienced the desired benefits, including decreased rates of depression corresponding to an increased participation in support groups and services, the appeal of the respite services increased. Grant staff acknowledged that the money did not go far; however, it was not designed to do so. After respite grant funds were exhausted, many individuals realized the benefit of the program and were more inclined to either purchase respite services out of pocket or use Medicaid benefits if they qualified. Providers also viewed the availability of direct service grants as an incentive to offer respite services. Having an adult day consultant available to support adult day care program start-up served as an additional incentive for providers.

Among the lessons to be learned from the Colorado ADDGS Grant program are that effective educational interventions for family caregivers and infrastructure development in rural areas require:

- *An understanding of the cultural and philosophical background of potential participants.* When implementing the Savvy Caregiver Program, it became clear that this curriculum would not be particularly appealing to the Hispanic population. Therefore, a separate set of training programs was developed to support individuals who speak Spanish only. Similarly, because of the "frontier spirit" of many of the state's family caregivers, it was necessary to develop an incentive for family caregivers to obtain respite services. By providing cash respite grants to allow family caregivers to "try out" supportive services, many individuals became much more willing to obtain respite support.
- *Flexibility and willingness to adapt the evidence-based model to meet local community needs.* The Alzheimer's Association Colorado Chapter quickly learned that continuing to follow the 6-week, 2-hour per week format for the Savvy Caregiver Program was not going to be successful in this largely rural state. After having conducted some research at Colorado State University to determine that changing the structure of the course would not adversely affect the program, ADDGS Grant staff decided to allow regional coordinators to determine the length and structure of their training sessions.

- *The development of infrastructure to promote the creation of adult day care programs.* By hiring an adult day care consultant to help communities develop programs, the ADDGS Grant contributed to building infrastructure to support family caregivers. This infrastructure was the result of collaboration among Grant staff, seed money from Systems Change for Real Choice grants for two programs, the local leadership and community awareness provided by Area Agencies on Aging, and motivated community members. Other states interested in implementing the Savvy Caregiver Program are encouraged to develop a system that promotes the necessary infrastructure of supportive services.
- *The development and ongoing refinement of evidence-based evaluation tools to monitor program performance and assess effectiveness over time.* Colorado State University staff saw the value of monitoring grant activity to determine program performance and justify the use of continued federal funds. Results of their evaluation, conducted 6 months after caregivers participated in the Savvy Caregiver training, indicated that rural participants who completed surveys and questionnaires both before the training and at the 6-month follow-up used the printed material and CD with some frequency following the training, had structured meaningful activities for the person with dementia, reported lower depression scores at follow-up, and increased their use of support groups (Smith and Bell, in press). Other states interested in implementing a similar program will likely need to develop a similar tracking/monitoring system to determine their program's effectiveness over time.

Although it is too soon to determine the long-term effects of the FY 2002-2005 ADDGS Grant, previous evidence-based research suggests that by providing the Savvy Caregiver training and respite grants, the state will succeed in providing caregivers of individuals with Alzheimer's disease the means to increase their skills, knowledge, and confidence, resulting in decreased stressors associated with caregiving and thereby providing better care for their loved one and themselves.

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