

January 2006

Implementing Evidence-based Models and Promising Practices: The Experience of Alzheimer's Disease Demonstration Grants to States (ADDGS) Programs

Executive Summary

Prepared for

Lori Stalbaum, M.S.W.
Administration on Aging
1 Massachusetts Avenue, NW
Washington, DC 20001

Prepared by

Donna J. Rabiner, Ph.D.
David Brown, M.A.
Deborah Osber, M.P.H.
Joshua M. Wiener, Ph.D.
RTI International
Health, Social, and Economics Research
1615 M Street, NW, Suite 740
Washington, DC 20036

RTI Project Number 0209351.001.008

**IMPLEMENTING EVIDENCE-BASED MODELS AND PROMISING PRACTICES:
THE EXPERIENCE OF ALZHEIMER'S DISEASE DEMONSTRATION GRANTS TO
STATES (ADDGS) PROGRAMS**

Donna J. Rabiner, Ph.D.
David Brown, M.A.
Deborah Osber, M.P.H.
Joshua M. Wiener, Ph.D.

AoA Project Officer: Lori Stalbaum, M.S.W.

RTI International*

Contract No. GS-10F-0097L 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. This report is a product of the Alzheimer's Disease Demonstration Grants to States National Resource Center. 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.

IMPLEMENTING EVIDENCE-BASED MODELS: THE EXPERIENCE OF ALZHEIMER'S DISEASE DEMONSTRATION GRANTS TO STATES (ADDGS) PROGRAMS

What is the ADDGS Program?

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).

Purpose

The purpose of these case studies is to provide information to states, consumers, and providers on how the U.S. Administration on Aging's Alzheimer's Disease Demonstration Grants to States programs in California and Colorado implemented evidence-based programs in their respective communities. The case studies:

- Document evidence-based practice and promising practices.
- Identify policy issues in providing services to people with Alzheimer's disease and their families.
- Identify implementation barriers and ways of overcoming them.
- Demonstrate how ADDGS programs can become more evidence-based and use promising practices, which is a goal of the U.S. Administration on Aging.

What is Evidence-Based Practice and Replication of Promising Practices?

Two of the themes of the federal, AoA-initiated 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. By implementing evidence-based approaches or replicating promising practices, states adopt well-established programs from other communities and apply lessons previously learned in building successful models to support individuals with Alzheimer's disease and their families. 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 Resources 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 training 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 impact of the initiatives can be objectively determined.

- *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 was not evaluated using rigorous evaluation methods.

Methodology

Programs in two states, California and Colorado, were chosen for case studies because they implemented evidence-based programs or promising practices (Brown, Rabiner and Wiener, 2006; Osber, Rabiner and Wiener, 2006). Information for these case studies was gathered by reviewing administrative files at the U.S. Administration on Aging and agency Web sites and by conducting in-person site visits in the two states in June through August 2005. As part of the site visits, RTI staff interviewed ADDGS staff, educators, researchers, representatives of consumer groups, volunteers, and providers.

Overview of Programs in California and Colorado

California: The state's initial project, El Portal: Latino Alzheimer's Project, began in 1992 and provided innovative dementia care and information to the Latino population in Los Angeles. Implemented by the Alzheimer's Association chapter in Los Angeles, the El Portal project brought together mainstream agencies, with their technical understanding of Alzheimer's disease and dementia, with ethnic-based community agencies, with their expertise in cultural competence. These two groups of partners formed Dementia Care Networks to provide the Latino community with an array of community services for persons with Alzheimer's disease and their families. The El Portal model proved to be both a promising intervention with Grant support and a model promoting enduring change in community dynamics and service delivery.

Culturally competent Care Advocates were recruited and trained to assess the needs of caregivers through an in-home evaluation and to connect the caregivers with Network services. The Care Advocates helped family caregivers coordinate Alzheimer's care by conducting outreach and community education to identify families needing services; assessing, educating, supporting, and connecting families to the services provided by the network; helping clients understand and respond to governmental regulations and requirements; and leading support groups.

El Portal also conducted an intensive public relations and outreach campaign including print and electronic media and making presentations to consumer and provider groups and at community fairs (Aranda, 2003). Since the mid-1990s, the model has been adapted for use in the African American community and has been widely reported on and replicated in other parts of the country. An Alzheimer's Disease Demonstration Grant in 2001 used the model to develop a system of dementia care for Asian and Pacific Islanders in the Los Angeles and San Francisco

areas. The current ADDGS Grant to California for 2004-2007 also serves Asian and Pacific Islanders in Los Angeles and San Francisco, developing Dementia Care Networks to enhance the capacity of local health and social service providers to serve Vietnamese, Korean, and Chinese dementia-affected families.

Colorado: The state's initial evidence-based project, the Savvy Caregiver Program, was implemented as a pilot program in Denver, Colorado, in 2000. 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 Minnesota 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 effectively carry out the caregiving role (Hepburn et al., 2003). Partnering with the Colorado Alzheimer's Association, the Colorado State Board of Agriculture, acting by and through Colorado State University, received an ADDGS Grant in 2002.

The overall goal of the Grant was to increase access to supportive services to caregivers in rural areas of the state. The initiatives implemented by the Colorado Alzheimer's Association and evaluated by Colorado State University included the Savvy Caregiver Program and consumer-directed respite grants of \$1,000 per year per family. Participants were recruited through the seven regional offices of Colorado's Alzheimer's Association, the Area Agencies on Aging, and the statewide outreach campaigns. The evaluation conducted by Colorado State University determined that participation increased caregiver skills and confidence, created reliable and accessible networks of support for caregivers, and increased access to supportive services (Smith and Bell, 2004). A second ADDGS Grant was awarded in July 2005 and is designed to build on the prior project by continuing the Savvy Caregiver training and providing respite grants and 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, 2005).

Obstacles and Solutions

California and Colorado faced a number of obstacles and developed a variety of solutions to successfully implement evidence-based Dementia Care Networks and Savvy Caregiver training programs in their respective communities. Other states, consumers, and providers interested in implementing evidence-based programs to support caregivers and individuals with disabilities can adopt these solutions. These obstacles and solutions included:

- *Adapting the intervention/program to different cultures.* ADDGS grantees that serve large minority populations need to have a sensitivity to and understanding of the cultural practices and beliefs of the communities they serve. In California, when implementing the Hispanic-based El Portal in the African American and Asian and Pacific Islander communities, project staff recognized the need to address local community culture, such as the view in some of the Korean and Chinese communities that people with Alzheimer's disease were being punished for being bad or were cursed. Another challenge was the need for sensitivity to community religious beliefs,

such as in the power of folk healers and shamans to cure disease, and the need to incorporate a tolerance of these attitudes in the Care Advocate's approach to establishing relationships with caregivers. In Asian American communities, the official caretaker of parents is typically the oldest son, but it is usually the son's wife or the oldest daughter who does the actual caretaking. Care Advocates have learned that it is necessary to go through the process of contacting the son before approaching the actual caretaker.

Similarly, in Colorado, recognizing that the Savvy Caregiver program was not appealing to the Spanish-speaking population, the Colorado Alzheimer's Association pilot tested two programs specifically designed to recruit Hispanic caregivers. These 1-hour presentations, to be used at churches or with civic groups, were designed to create an entry into other services provided by the Colorado Alzheimer's Association. In addition, the Colorado ADDGS addressed barriers from the rural population by adding flexibility to the format and number of Savvy Caregiver training sessions offered in geographically remote areas.

- *Translating information into a language spoken by caregiver families.* Grantees that serve populations with a large number of dialects spoken need to translate their evidence-based programs into dialects that are meaningful and understandable to their target audiences. In the California program, the large number of Chinese dialects is an ongoing problem in serving that community, in part because it creates difficulties in completing the intake forms and compromises the form's function as a data-gathering tool for evaluative research. The number of dialects also has made it difficult to develop support groups for Chinese caregivers. In dealing with the intake form, the Care Advocates employed their own knowledge of dialects when possible and, when that was not possible, tried to get assistance from a service provider.
- *Adapting research-oriented data collection to community programs.* Because many people served by ADDGS Grants may be uncomfortable responding to personal questions about their background and experience as a caregiver, it is important for evidence-based programs to explain why caregivers should try to answer these questions—both to help them obtain needed services and to help project staff evaluate the impact of their use of ADDGS services. In California, the ten-page intake form used under the first Asian and Pacific Islander Grant, though useful for data collection, asked many questions about the family's private life. Caregivers were often embarrassed in responding to the questions, and the Care Advocates reported that it could take many visits to complete the form, restricting the time available for counseling the family and planning services. The Los Angeles Chapter decided to stop using this form and substituted a new, much shorter and less personal intake form, which is facilitating their contacts with caregivers.
- *Adapting the research-validated program to rural communities.* To successfully implement evidence-based programs in rural community settings, ADDGS Grant staff needed to find creative ways to minimize travel without compromising the integrity of the evidence-based approach. The Savvy Caregiver training was originally designed to be conducted over a 6-week period with 2 hours per session. Because of

the amount of time involved in traveling long distances and the training itself, the Colorado ADDGS Grant staff condensed the material into a 1-, 2-, or 3-day format during consecutive weeks, thereby reducing the number of weekly trips by at least 50 percent, with no significant impact on the effectiveness of the training (Scharf et al., 2005). To be responsive to the needs of the regional offices, the Colorado Alzheimer's Association now allows each regional coordinator to select the training format of his/her choice.

- *Making sure that key elements of the evidence-based program are implemented.* To achieve the benefits of an evidence-based program, the key elements of the model must be implemented. This is particularly difficult to accomplish when programs are geographically dispersed. In Colorado, each of the seven district coordinators conducts the Savvy Caregiver trainings in their respective regions; some regions also have trained volunteers who conduct the Savvy Caregiver Program trainings. To ensure that the program material is presented consistently across the state, the Alzheimer's Association created a syllabus for each session to capture the most important points. While coordinators are given considerable latitude in the additional material included in the training sessions, they are required to cover the central office-determined "essential information" during each set of training sessions.
- *Continuing to monitor effectiveness of program.* ADDGS programs that use evidence-based programs need to monitor both initial ADDGS implementation and ongoing project performance to (a) determine whether the community-based program is being true to the initial evidence-based model and (b) evaluate whether the impact/benefit of the program is similar to that reported by the initial developers of the evidence-based model. In California, El Portal engaged in a significant amount of data gathering and analysis. The U.S. Administration on Aging-funded evaluation of the ADDGS program reported on the overall developments in the program, and the Los Angeles Chapter of the Alzheimer's Association gathered extensive data on the clients and families it served (Montgomery, 2002). The Los Angeles Chapter used these data for its own assessment process, employing a series of experts from area universities to research a journal article outlining the organization of the Grant and the Dementia Care Networks, describing the cultural characteristics of the target population, and analyzing the service utilization under the Grant (Aranda, 2003). Colorado State University staff members saw the value of monitoring Grant activity to document program performance and to justify continued federal support. University-based research staff also plan to monitor and refine the tools used to evaluate the current ADDGS project over time.

In summary, these case studies present evidence-based approaches and promising practices, identify policy issues relevant to individuals with Alzheimer's disease and their families, and discuss obstacles and ways of overcoming them. The key question addressed in both case studies is how to successfully adapt key elements of an existing or previous intervention into a community setting different from which the model was originally designed. By implementing evidence-based approaches and replicating promising practices, states can adopt well-established interventions from other communities and apply lessons previously

learned to build successful initiatives that support individuals with Alzheimer's disease and their families.

Further Information

The full case studies are available at <http://www.aoa.gov/alz>. For further information, please contact Joshua M. Wiener, Ph.D., Co-Director of the Alzheimer's Disease Demonstration Grants to States National Resource Center at (202) 728-2094 or jwiener@rti.org or Diane Braunstein, Technical Assistance Director of the Alzheimer's Disease Demonstration Grants to States (ADDGS) National Resource Center at (202) 638-8664 or diane.braunstein@alz.org. For information about the U.S. Administration on Aging's Alzheimer's Disease Demonstration Grants to States (ADDGS) program, please contact Lori Stalbaum, ADDGS Project Officer, at (202) 357-3452 or lori.stalbaum@aoa.hhs.gov.

References

- Colorado Alzheimer's Project: ADDGS Grant Application. Fort Collins, 2005.
- Aranda, M., Villa, V., Trejo, L., Ramirez, R. and Ranney, M.: El Portal Latino Alzheimer's Project: Model program for Latino caregivers of Alzheimer's disease-affected people. Social Work 48(2):259-271, 2003.
- Brown, D., Rabiner, D. and Wiener, J. (2005). Alzheimer's Disease Demonstration Grants to States: California Asian and Pacific Islander Dementia Care Networks. Draft report prepared by RTI for the Administration on Aging.
- Hepburn, K.W., Lewis, M., Sherman, C.W. and Tomatore, J.: The Savvy Caregiver Program: Developing and testing transportable dementia family caregiver training program. The Gerontologist, 43:908-915, 2003.
- Montgomery, J.: (Ed.) A New Look at Community-Based Respite Programs—Utilization, Satisfaction, and Development. Binghamton, NY. Haworth Press, 2002.
- Osber, D., Rabiner, D. and Wiener, J. (2005). Alzheimer's Disease Demonstration Grants to States Program: Colorado Savvy Caregiver Training Program. Draft report prepared by RTI for the Administration on Aging.
- Scharf, L., Bell, P.A. and Smith, S.A.: Evaluation of formats of one, two or three sessions for Alzheimer's savvy caregiver training. Manuscript under review, 2005.
- Smith, S.A. and Bell, P.A.: Examining the effectiveness of the savvy caregiver program among rural Colorado residents. Manuscript under review, 2004.
- U.S. Administration on Aging: About AoA Alzheimer's Disease Demonstration Grant Program. http://www.aoa.gov/alz/public/alzabout/aoa_fact_sheet.asp, no date.