September 2014

The Alzheimer's Disease Supportive Services Program: 2014 Report on Completed Grants

Final Report

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EXECUTIVE SUMMARY

In 2014, more than 5 million Americans of all ages have Alzheimer's disease. Because Alzheimer's disease destroys basic cognitive skills, it places a large burden on people with the disease and their caregivers. To improve services for this population, Congress established the Alzheimer's Disease Supportive Services Program (ADSSP), which is administered by the Administration on Community Living (ACL)/Administration on Aging (AoA).

This report summarizes the experience of 60 completed ADSSP grants initially funded by ACL/AoA between 2007 and 2010, including 45 Innovative Practices and 15 Evidence-Based grants. Innovative Practices grants use a variety of approaches to improve the delivery of supportive services at the community level. These approaches have some foundation in research, but have not been rigorously tested in randomized clinical trials. Evidence-Based grants translate interventions that have been tested through randomized-controlled clinical trials with the results published in peer-reviewed journals. The 60 ADSSP grants included in this report served 28,227 people over the course of their grant period, including 13,571 persons with dementia and 14,656 caregivers.

The Innovative Practices grants focused on outreach and services to people in the early stages of dementia and their families, creation and enhancements of dementia care networks, and helping persons with dementia avoid nursing home placement. Two Innovative Practices grants implemented a modified version of the Evidence-Based program Resources for Enhancing Alzheimer's Caregiver Health (REACH) II called REACH OUT. The Evidence-Based grants address the following interventions: Coping with Caregiving, the New York University Caregiver Intervention (NYUCI), Reducing Disability in Alzheimer's Disease (RDAD), REACH II, Savvy Caregiver, Skills2Care, and STAR-C.

Across all types of grants, some of the most common project activities included care consultation, respite/adult day care, education, expansion/enhancement of referral and service networks, and community outreach. Most grants involved partnerships with Area Agencies on Aging (AAAs), the Alzheimer's Association, and universities. Other community organizations and public agencies were also involved in several grants.

Project outcomes varied greatly across grants. The target number of persons to be served was available for 25 of 60 closed grants. Of the 25, 17 grants (68%) achieved or exceeded their goal, 6 grants reached between 50% and 84% of their target, and 2 grants reached less than 50% of their target. Most grants targeted specific populations related to race/ethnicity, disease stage, risk of nursing home placement, or other criteria. Thirty-seven grants out of 60 (62%) appear to have reached or partially reached their specific target populations.

Although Evidence-Based programs were required to have an evaluation of their impact, Innovative Practices projects did not have this requirement. Nonetheless, some Innovative Practices grants did conduct evaluations. Among the innovative practices and evidence-based interventions grants that used pre/post measures or experimental designs to evaluate their programs, positive change was common in the areas of caregiver depression/stress/burden/coping ability and caregiver knowledge/competence. For most Innovative Practices and Evidence-Based interventions grants, evaluations used simple research designs and lacked control or comparison groups; small sample sizes were common among the evaluations.

Fifty-two of 60 grants are continuing or partially continuing after the end of the grant. AAAs and the Alzheimer's Association are frequently involved in continuing grant programming, and many grants are also receiving ongoing funding from the Older Americans Act, state governments, and private foundations.

SECTION 1:
INTRODUCTION AND BACKGROUND

In 2014, more than 5 million Americans of all ages have Alzheimer's disease. Older age is the primary risk factor for Alzheimer's disease and most other dementias (Morris, 2005). As a result, the number of Americans with these conditions is expected to increase rapidly as the number of older people grows. Without a research breakthrough to prevent Alzheimer's or delay its onset or progression, the number of people with the disease is expected to reach a projected 13.8 million by 2050 (Hebert et al., 2013).

Dementias, which include Alzheimer's disease, damage brain cells and the connections among them, thus affecting an individual's cognitive and physical functioning and behavior. Although memory loss is a signature symptom of dementia, these diseases also cause loss of executive function, judgment, orientation, and the ability to understand and communicate effectively, to speak or understand spoken or written language, to recognize or identify objects, to think abstractly, and to make sound judgments and plan and carry out complex tasks. In 2013, 15.5 million caregivers provided an estimated 17.7 billion hours of unpaid care for people with Alzheimer's and other dementias (Alzheimer's Association, 2014).

States serve a substantial number of people with dementia and their family caregivers in their Aging Networks and long-term services and supports systems. Serving this population effectively involves accommodating the needs of a population that, in addition to memory loss, experiences a variety of physical, cognitive, and behavioral symptoms resulting from dementia, along with other medical conditions.

In 1992, Congress created the Alzheimer's Disease Demonstration Grants to States (ADDGS) Program to improve home and community-based services for people with Alzheimer's disease and related dementias (ADRD) and to assist families in obtaining appropriate services. As specified in the authorizing legislation, the goals of the ADDGS program are to:

- Expand the availability of diagnostic and support services for persons with ADRD, their families, and their caregivers
- Improve the responsiveness of the home and community-based care system to persons with dementia
- Develop models of assistance for persons with ADRD and their family caregivers

- Encourage close coordination and incorporation of ADRD services into the broader home and community-based care system

- Target hard-to-reach communities and underserved persons with dementia and their families

For most of its history, the ADDGS program funded states to develop a very wide range of services for people with Alzheimer's disease and their caregivers. In 2008, the Administration on Aging (AoA) redesigned the program to focus more on evidence-based and evidence-informed programs. The program also was renamed the Alzheimer's Disease Supportive Services Program (ADSSP) in 2009. As part of the continuing evolution of the ADSSP program, AoA awarded grants in 2011 to develop and implement more integrated long-term services and supports systems at the state and local levels and to make them more dementia capable.

Currently, the ADSSP program has three types of grants:

- **Evidence-Based** grants translate interventions to community settings that have been tested through randomized-controlled clinical trials with the results published in peer-reviewed journals. Through rigorous study, these evidence-based models have been shown to improve the health and well-being of persons with ADRD or their caregivers. These grants translate interventions to community settings that were typically originally tested in a university environment.

- **Innovative Practices** grants use a variety of approaches to improve the delivery of supportive services to people with ADRD and their family caregivers. Intervention categories include evidence-informed interventions, promising practices, and systems redesign. Evidence-informed and promising practices encompass some evidence base but are generally less rigorous, more experimental, and shorter in duration without a required evaluation. One subset of Innovative Practices grants, systems redesign grants, focused on enhancing the ability of health and long-term supportive services systems to serve persons with dementia and their caregivers.

- **Systems Integration/Dementia Capability** grants seek to ensure access to a sustainable, integrated long-term services and supports system that is capable of meeting the needs of persons with dementia and their caregivers to help them remain independent and healthy in the community. Key components of a dementia-capable system include identification of a suspected cognitive impairment, workforce training on dementia, and provision of services that address the unique needs of people with dementia and their caregivers (Gallagher-Thompson et al., 2002; Tilly et al., 2011).

This report is a summary of the experience and outcomes from 60 grants funded between 2007 and 2010, including 45 Innovative Practices and 15 Evidence-Based grants. These grants were completed and filed their final reports no later than May 31, 2014. This report is based primarily on the Final Reports submitted by the 60 grants; in a limited number of grants, previous semiannual reports and other documents submitted by the grantee were also reviewed. Information on each completed grant was abstracted using a standard template, which included a number of domains including a description of the intervention, program goals and objectives, activities, outcomes, challenges, innovations, sustainability, and recommendations for future efforts.

Following this introductory and background section, this report provides an overview of the projects, a description of the innovations and evidence-based interventions, a synthesis of program outcomes, a description of challenges faced by the projects, the ability of projects to continue after ADSSP funding ends, and conclusions about the 60 projects. ***Appendix A*** lists the grants analyzed in this report. ***Appendix B*** presents more detailed case studies of 10 grants—seven Evidence-Based grants—Arizona, California, Minnesota, New Jersey, North Carolina, Ohio, and Oregon—and three Innovative Practices grants—Georgia, Kansas, and Minnesota.

1.1 Overview of Grants

1.1.1 Topic Areas

The Innovative Practices and Evidence-Based grants addressed many interventions. The Innovative Practices grants can be grouped into four categories: Early-Stage Dementia Programs, Nursing Home Diversion, Dementia-Capable Networks/Systems, and Resources for Enhancing Alzheimer's Caregiver Health (REACH) OUT. The Evidence-Based grants can be grouped into seven categories: Coping with Caregiving, NYUCI, RDAD, REACH II, Savvy Caregiver, Skills2Care, and STAR-C.

Innovative Grants

The Early-Stage Dementia Programs covered in this report include 14 grants in 13 states (Alabama, Arizona, Colorado, Florida, Georgia, Minnesota, Missouri, Nevada, Ohio, Oklahoma, Rhode Island, Utah, and Virginia). The main focus of Early-Stage Dementia Programs was reaching persons with dementia and their caregivers early in the disease process to allow for better treatment and to engage persons with the disease in their own care and planning. All interventions employed a multipronged approach, including community outreach, assessment, education, respite, and care consultation. Unique interventions included use of televideo services to reach rural residents with diagnostic and support services, neurolinguistic programming to reduce depression, meditation or expressive writing to reduce caregiver burden, driving assessments for persons with early to mid-stage Alzheimer's disease, and weekly clinical counseling sessions for persons with the disease.

The Nursing Home Diversion projects include 15 grants in 14 states (Connecticut, Georgia, Idaho, Indiana, Louisiana, Maine, Massachusetts, Michigan, Missouri, Tennessee, Texas, Utah, Virginia, and Washington). Nursing Home Diversion projects had the goal of helping persons with dementia avoid nursing home placement, enhancing their quality of life by enabling consumers to stay at home, and reducing expenditures. Frequently used strategies included care consultation for families, education of caregivers on dementia and caregiving strategies, improvements in the ability of families to direct their own care options, the provision of respite and day care services, better identification of families at risk of placing their loved one in a residential facility, and improved coordination of services among agencies that help those affected by dementia. Maine took a unique approach, focusing on depressed caregivers.

The Dementia Capable Networks/Systems projects include 14 grants in 10 states (California, Kansas, Maine, Minnesota, New Hampshire, New Mexico, North Carolina, South Carolina, Tennessee, and Wisconsin). These nine projects had a central goal of creating or improving dementia-capable networks and systems to improve the likelihood that individuals with dementia would be identified and receive appropriate services. The focus of the grants varied. One project worked on establishing connections between health, aging, and social service organizations and particular ethnic communities. Another strove to serve families struggling with the neuropsychiatric complications of depression (such as anxiety or psychosis) by bridging the aging and mental health systems. A third grant implemented a referral program to help provide linkages to services for people not eligible for publicly funded programs. Another grant worked to improve the well-being of persons with dementia within a specific healthcare system by educating providers and staff on assessment, enhancing electronic records to include information about care plans, and connecting families with a dementia care specialist. Seven grants worked to strengthen ties between the dementia services community and primary care physicians, primarily through outreach to and education of physicians; one of these grants also established formal connections between family care consultants and faith-based organizations.

The REACH OUT projects include two grants in Puerto Rico and Vermont that implemented an abbreviated version of the Evidence-Based REACH II program. The REACH OUT program aims to promote the health and well-being of caregivers through a series of in-home sessions offered over the course of several months. Case managers worked with caregivers to problem solve and develop written action plans pertaining to in-home safety, caregiver health, caregiver emotional well-being, behavioral management, and enhanced social support.

Evidence-based Grants

The evidence-based Coping with Caregiving psychoeducational group intervention (two grants in Arizona and Nevada) was translated into a community-based program: Care Partners Reaching Out (CarePRO). The program provided regular workshops with family caregivers, and follow-up homework and coaching to help improve caregiving skills in the home.

Three states—California, Georgia, and Minnesota—implemented the NYUCI program, which supports caregivers through one initial caregiver counseling meeting, four family sessions, and a subsequent caregiver counseling meeting, as well as additional caregiver consultant time for additional assessments and support to the caregiver and family. In Minnesota, NYUCI was translated and then expanded to additional regions of the state, while in Georgia, the project was carried out in two Area Agencies on Aging (AAA) regions. California's program delivered NYUCI in the Los Angeles and San Francisco metropolitan areas with a focus on Chinese, Japanese, and Latino caregivers.

One grant project in Ohio implemented RDAD, a program that provides support and services through an in-home, physical exercise program for persons with dementia and behavior modification skills training for the family caregiver. The program was piloted in northwest Ohio and then expanded to other regions of the state.

Five grants, including one in Florida, two in Georgia, and two in North Carolina, used the evidence-based REACH II model, which provides both in-person and telephone support for caregivers over a 6-month period, including education on the disease, strategies on enhancing safety and managing challenging behaviors, encouragement of self-care and use of social support, and managing stress and depression among caregivers. The Florida grant was intended to serve low-income and minority caregivers, while the Georgia grant targeted rural caregivers, and both North Carolina grants tried to reach rural, low-income, and minority caregivers.

Three grant programs implemented the evidence-based Savvy Caregiver training intervention: in California, the program was targeted to English-speaking African American, Asian/Pacific Islander, and Latino caregivers throughout the state; grants in Maine and Michigan aimed to make Savvy Caregiver available statewide, including among the states' many rural residents.

A New Jersey project translated the Philadelphia REACH evidence-based research—the Home Environmental Skill-building Program (ESP)—into a direct service intervention:

Skills2Care™. Skills2Care™ is a home-based program in which occupational therapists help family caregivers to manage challenging behaviors of persons with ADRD.

Finally, an Oregon grant implemented a translation of the home-based behavioral intervention STAR-Caregivers (STAR-C), which aims to decrease depression and anxiety in individuals with Alzheimer's disease and their family caregivers. This version of STAR-C used case managers to deliver four home visits and six follow-up phone calls, teaching about challenging behaviors, problem-solving, and also providing basic information on Alzheimer's disease and community resources.

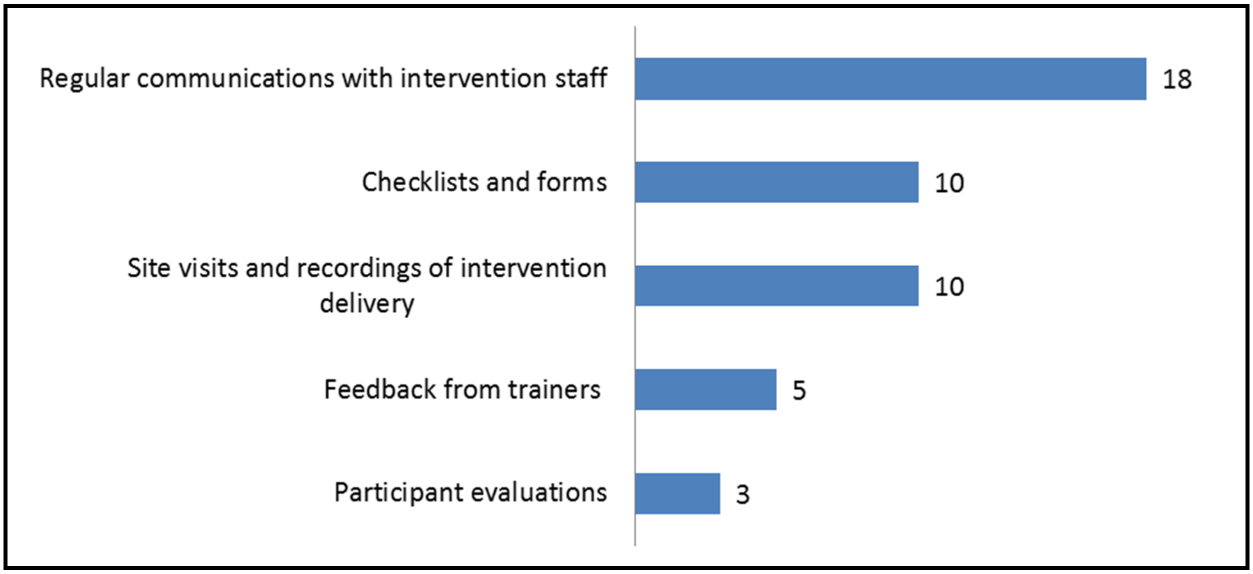
1.1.2 Fidelity Monitoring

Fidelity monitoring is designed to ensure that interventions are implemented as intended. For evidence-based interventions, fidelity monitoring is intended to ensure that the project is implementing the original intervention or the original intervention as specifically modified by the community translation project. In theory, implementing the same intervention should help ensure that the outcomes of the original intervention are achieved in the community setting. For Innovative Practices grants, fidelity monitoring ensures that what is implemented is not different from what was approved by the Administration on Community Living/AoA.

Projects used various mechanisms for monitoring fidelity. Thirty-one of the 60 grants reported that they monitored the fidelity of the intervention. Fourteen of these indicated specifically that the program did maintain fidelity with the planned intervention, while the other 17 reported the type but not results of fidelity measures used. (One of the grants that reported successfully maintaining fidelity did not provide any details on how fidelity was monitored.) The most common types of fidelity measures are reported in ***Exhibit 1.***

Grants implementing the Savvy Caregiver program incorporated some of the most thorough fidelity measures. In California, each Alzheimer's Association chapter delivering the Savvy Caregiver program used special monitoring tools to ensure model fidelity and to monitor trainer quality. These tools included (1) consumer satisfaction surveys, which were reviewed after each session to determine whether any changes could be made to improve delivery; (2) feedback forms about the trainer, completed after each session to assess whether the trainer should modify the session and if so, how; (3) digital voice recordings, used to tape the second course the trainers delivered (this practice was later replaced with spot-checking and debriefing meetings with trainers); (4) a master trainer, who attended at least one session to spot-check performance; and (5) mentoring and shadowing of less experienced trainers or those less comfortable with the intervention to provide feedback.

Exhibit 1.
Number of Grants Using Various Means of Ensuring Fidelity



SOURCE: ADSSP National Resource Center analysis of grantee final reports.

Grants used several means of ensuring that the intervention was delivered as intended. The most common method utilized was regular communications with intervention staff, which was employed by 18 grants and often took place via periodic teleconference calls. Ten grants used checklists and forms to confirm that critical content was delivered, 10 grants used a combination of site visits and/or recordings of the program being delivered, five grants solicited feedback from trainers, and three grants used information gathered from participants on evaluation forms.

The Maine Savvy Caregiver project also used multiple means of ensuring fidelity, including (1) developing a structured training program for all Savvy Caregiver Program trainers, (2) oversight of associate trainings by master trainers, (3) incorporating a training checklist into the procedure manual, (4) analyzing workshop evaluation results, (5) submitting a fidelity checklist following each training, (6) observational visits made by the project coordinator, and (7) including formal discussions of fidelity in team meetings.

The Minnesota NYUCI Expansion grant, called Family Memory Care, used multiple tools to ensure fidelity to the NYUCI model: (1) all Family Memory Care consultants were trained in the key components of the intervention, including assessment, individual and family sessions, and ad hoc contacts; (2) the Family Memory Care Clinical Director provided group guidance to the Family Memory Care consultations via 90-minute monthly conference calls using case presentations and individual guidance via phone or e-mail consults; and (3) the Family Memory Care consultant completed a Microsoft Excel Caregiver Status Sheet after each contact to track the progress of each caregiver and family, using at least 12 data points including assessments, session dates, ad hoc contacts, and placement, bereavement, or drop dates.

In the Georgia Caregiver Assessment and Nursing Home Diversion program, a process evaluation was conducted to ensure proper implementation of the Tailored Caregiver Assessment and Referral (TCARE®) process. TCARE® is a caregiver assessment and referral protocol designed to assist care managers. It provides care managers with a set of steps to move from the assessment to the implementation of a care plan. All TCARE® forms completed for each caregiver were reviewed by staff at the time of the baseline, 6-month follow-up, and 12-month follow-up assessments. Each assessment was reviewed using a 27-item checklist and assigned scores for two measures of fidelity. The mechanics score is a measure of the extent to which the care manager correctly recorded information on the TCARE® forms (i.e., the assessment form, the assessment summary sheet, the care plan consultation worksheet, and the care plan). The process implementation score is a measure of the extent to which the care manager created a viable care plan that accurately reflected the TCARE® protocol. The process implementation score was created by reviewing the care plan consultation worksheet with the care plan using a nine-item inventory checklist. Two master's-level social worker members of the study team independently reviewed and scored all forms. When reviewers disagreed, they met to gain consensus. To ensure accurate and consistent compliance of the protocol throughout the project period, care managers whose average score was less than 70% on either dimension of fidelity were contacted by one of the two reviewers and offered technical assistance.

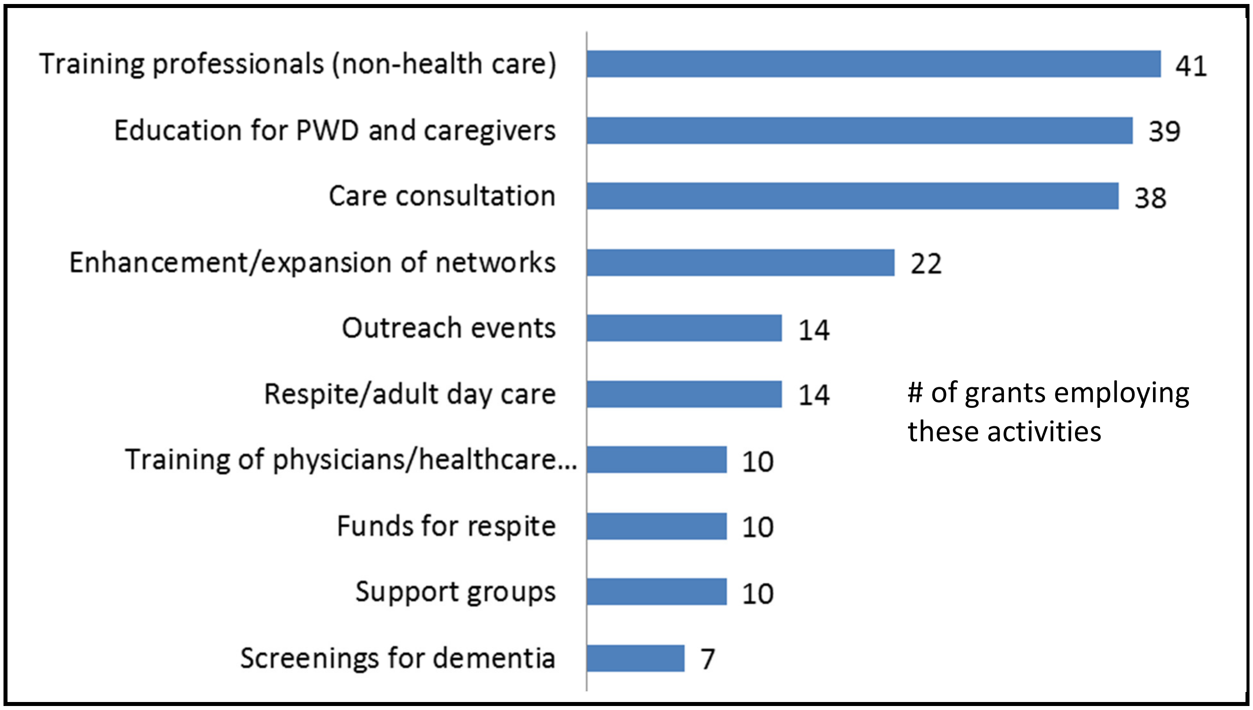
Activities Across Grants

The 11 groups of grants had considerable overlap of activities. Among all grants, professional trainings, care consultation/planning services, education, enhancement/expansion of community health networks, outreach, and respite/adult day care were commonly incorporated. ***Exhibit 2*** summarizes the activities of the grants and their frequency.

Types of Partners and Their Roles

ADSSP grants worked with many partners to implement their projects. ADSSP grant project partners fell into five main categories: Area Agencies on Aging (AAAs), Alzheimer's Association chapters, universities, other private organizations, and other public organizations. Forty-two grants involved chapters of the Alzheimer's Association. The Alzheimer's Association most often provided direct services to program participants (e.g., care consultations, education programs, or support groups) or marketing/outreach and referrals. The Association also conducted trainings, both for those affected by the disease and for professionals.

Exhibit 2.
Common Activities Across Grants



NOTE: These counts do not encompass every activity launched by every grant; rather, they reflect the key activities reported in summary reports for each grant.

PWD = people with dementia.

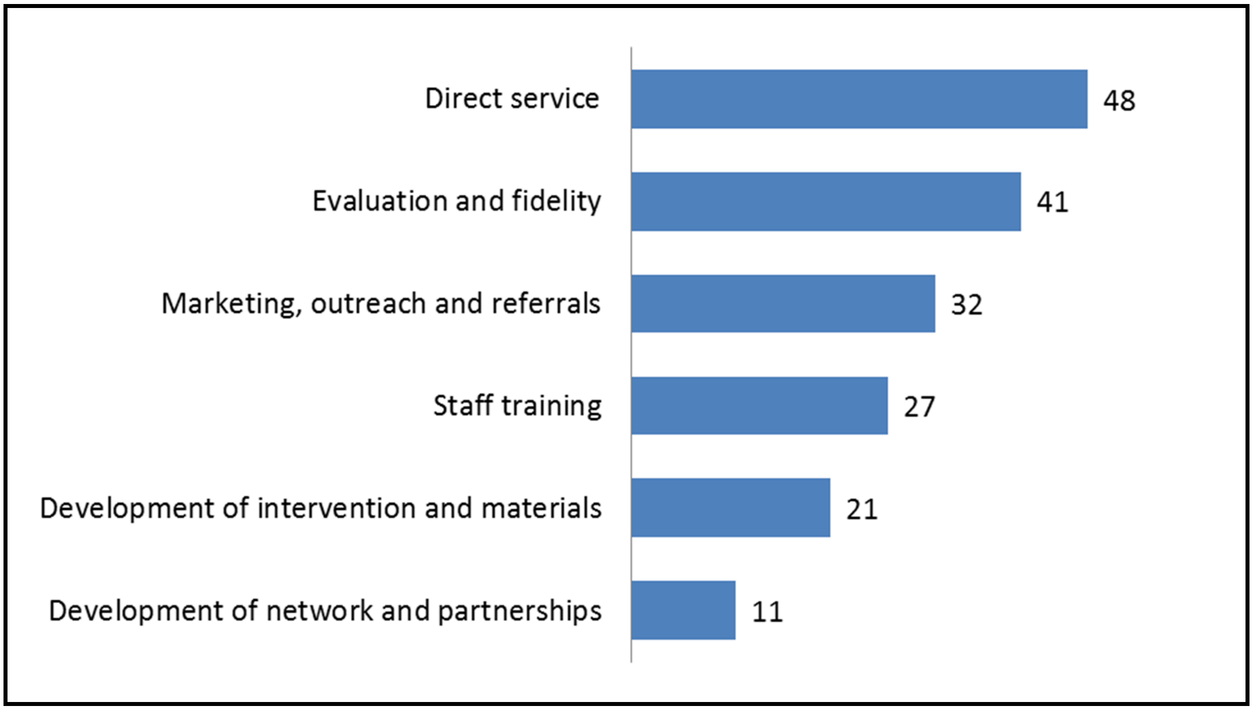
SOURCE: ADSSP National Resource Center analysis of grantee final reports.

Grant designs were based on a variety of evidence-based programs and had different focuses such as early stage intervention or nursing home diversion, but across these categories, they engaged in several common activities, including: training professionals (41 grants), education of PWD and caregivers (39 grants), and care consultation (38 grants). Other typical activities included development of community networks, outreach events, respite care, training for healthcare professionals and support groups.

One or more AAAs was involved in 40 grants; like the Alzheimer's Association, they primarily provided direct services, conducted outreach, and facilitated referrals; several AAAs also assisted with data collection and grant management. Forty grants received assistance from universities, primarily in evaluating program outcomes. University staff also participated in developing and conducting trainings for physicians, leading master trainings, developing interventions and protocols, and monitoring fidelity.

Thirty-nine grants involved various community nonprofit organizations, foundations, religious institutions, and other organizations to provide direct service, help develop the intervention and associated materials, and train staff, among other activities. Twenty-two grants included one or more public institutions beyond the state agencies receiving the grant. Eleven were state-level agencies, eight were aging and disability resource centers, three were regional/county agencies, and four were Department of Veterans Affairs (VA) facilities. The public entities played a variety of roles, providing marketing, outreach, and referrals; providing direct services; and developing services and materials. ***Exhibit 3*** shows the activities undertaken by various program partners.

Exhibit 3.
Number of ADSSP Grants Using Partners in Various Roles



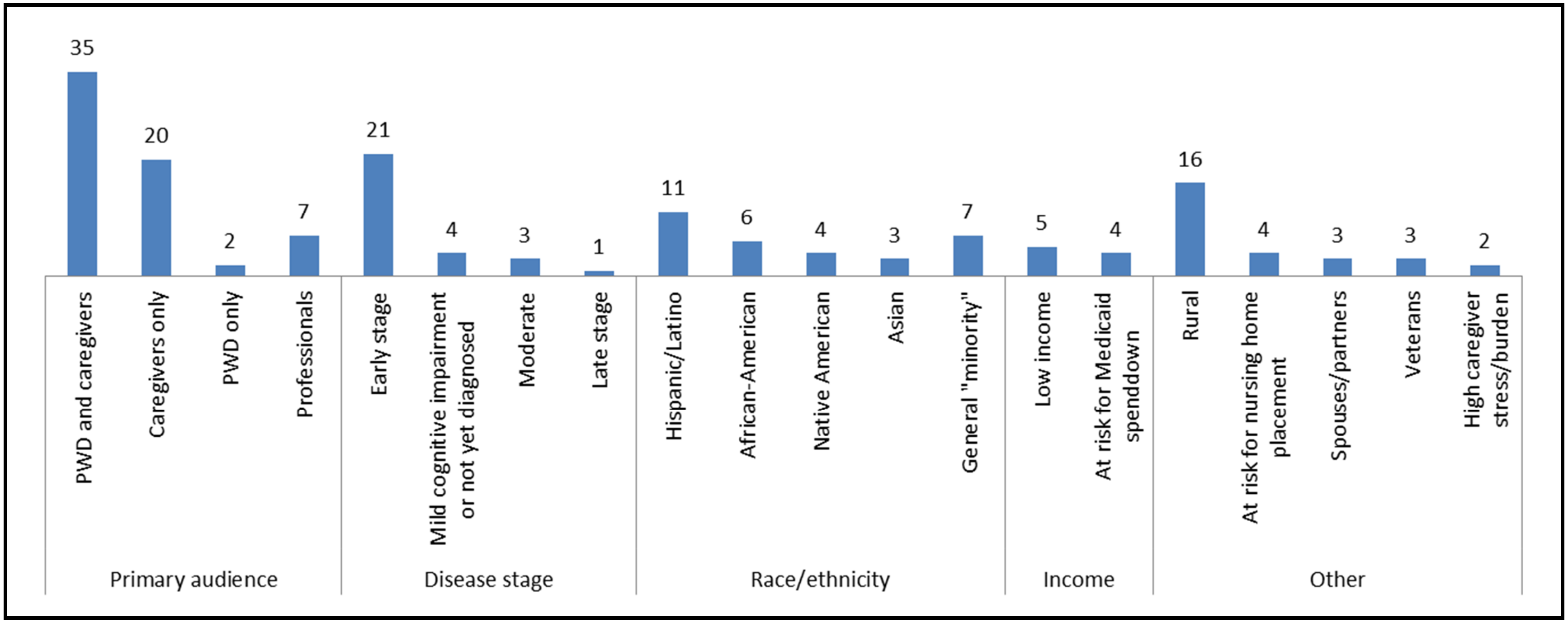
SOURCE: ADSSP National Resource Center analysis of grantee final reports.

Most grantees developed partnerships with governmental entities, healthcare providers, community organizations and/or university researchers. Those partners served in a variety of roles, including delivering services (48 grants), designing and/or conducting evaluations and monitoring fidelity (41 grants), reaching out to potential participants and other organizations (32 grants), and helping to train interventionists (27 grants).

1.1.3 Target Populations

All grants targeted some specific population(s) for their projects. Seventeen grants had multiple target groups or overlapping criteria. For example, the Nevada Early Stage Dementia Project grant targeted “financially compromised” persons with mild cognitive impairment or early-stage dementia, with an emphasis on Hispanic, American Indian, and rural populations. ***Exhibit 4*** summarizes the characteristics of the target population for these grants. Because grants targeted multiple audiences, totals may add to more than the total number of grants.

Exhibit 4.
Number of Grants with Specific Target Populations



NOTE: There were seven “Other” categories that applied to only one grant and that are not shown above: limited English, neuropsychiatric challenges, persons not seeking residential placement for at least 6 months, persons with dementia living in the community, persons with dementia with behavioral issues, persons over age 50, and persons over age 60.

PWD = people with dementia.

SOURCE: ADSSP National Resource Center analysis of grantee final reports.

All grants targeted specific population(s) for their projects, including persons in certain stages of the disease, racial or ethnic groups, income levels, or other variables such as rural locations or high risk of nursing home placement. Thirty-five grants targeted both PWD and caregivers with their interventions, while 20 grants served caregivers only. Other common targets included: early stages of the disease (21 grants), rural audiences (16 grants), and Hispanic/Latino individuals (11 grants).

1.1.4 Innovative Approaches

One of the goals of the ADSSP program is to pilot new approaches to serving people with dementia and their caregivers. Grantees explored new approaches on marketing and outreach, worker training, and infrastructure development.

Marketing and Outreach

Marketing and outreach as a way of increasing awareness of the program, and recruiting participants was a critical activity for these grants. California worked with ethnic media to promote events, inform caregivers of the project's services, and educate the general community about memory loss. Partnerships within the Vietnamese ethnic media community included using a Vietnamese newspaper and radio programs to publicize project events. The Vietnamese Care Advocate was also interviewed on a Vietnamese television program. The local Vietnamese newspaper, the *Nguoi Viet Daily News*, printed condensed fact sheets on a variety of Alzheimer's disease topics. The Vietnamese Care Advocate worked with the national Alzheimer's Association and two project clients to develop a video in Vietnamese presenting the 10 warning signs of dementia and sharing the experiences of two families seeking a diagnosis for cognitive impairment problems.

Oklahoma held an outreach event for the Hispanic community called *Healthy Mind in a Healthy Body*. The project used multiple grassroots recruitment efforts, including hosting the event at a church prominent in the community, using Hispanic community TV stations and newspapers to provide free advertising, and distributing 2,600 flyers. Community agencies provided translators for the event, and Hispanic restaurants provided food. Other community agencies partnered by hosting booths and providing prizes. A total of 421 persons attended, more than twice the goal.

In Alabama, a statewide memory screening initiative was held to raise awareness. Forty-three events took place in 34 counties (of 67 counties total); 870 individuals were screened. The project leveraged partnerships with community leaders, long-term care facilities support groups, and leaders in faith-based networks and used local media in creating awareness about the statewide memory screening initiative.

South Carolina used multiple means of marketing and outreach; perhaps most innovative was the mobile van used by the Aging and Disability Resource Center (ADRC) to provide outreach, education, assessments, and service options to individuals potentially affected by

ADRD and their families. The van operated in underserved rural areas of Charleston, Berkeley, and Dorchester counties and was equipped as a full-service “office on wheels.”

Another example of trying to bring programs to the people occurred in Michigan, where AAAs were encouraged to use sites where caregivers would feel comfortable; this meant familiar sites with free and easy parking. For example, a Savvy Caregiver program was held in the tribal community room in the same building as the tribal casino. Another barrier to participation was addressed by North Carolina, which used respite care as an incentive for participation in the REACH OUT program.

In Missouri, project staff worked in partnership with physicians to design a brochure/referral form that would simplify the referral process for physicians and explain the program to family members. This partnership between project staff and a core group of physicians has been an accomplishment of this program; developing ties with a larger group of physicians is ongoing. Physicians targeted for partnerships included neurologists, geriatric psychiatrists, and family physicians.

Georgia also sought input on materials, conducting focus groups to increase marketing effectiveness. The grantee created a detailed recruitment work plan and developed marketing materials early in anticipation of recruitment challenges. In Virginia, Connections partners and staff were all given the same set of talking points to ensure consistency across all entities involved in the project.

Many grants attempted to make contacts with religious institutions and leaders to reach particular racial and ethnic groups. Tennessee took this effort one step further by hosting clergy and lay leader conferences, followed up by workshops within the African American churches or community. The conferences and workshops were held to educate clergy and church leaders about the Alzheimer’s disease population; to provide opportunities for skill building, information sharing, and networking; and to allow for an exchange of ideas and strategies to improve services.

The Minnesota Chippewa Tribe site hosted major outreach events, such as an Honoring Elders and Elders Fall Feast, where tribal elders learned about early memory loss; many participants completed a memory loss quiz based on the “10 warning signs” modified for the American Indian community. The quiz was also given to home-delivered meal recipients, with more than 10% requesting additional information on early memory loss.

In New Mexico, presentations at the Title VI Coalition of American Indian senior center directors and visits with the directors were used to establish collaborative partnerships. Sessions provided to American Indian caregivers, including veterans, were co-presented with tribal representatives who served as interpreters.

Worker Training

For long-term services and supports systems to be dementia capable, staff need to be knowledgeable about ADRD, including detection and diagnosis, progression of the disease, communication techniques, and the unique needs of people with dementia and their caregivers. ADSSP projects provided training of interventionists and other staff involved in grant activities, and other paid caregivers not employed by the project.

The Georgia REACH project included a thorough training process for group leaders and interventionists: the research team from the Rosalyn Carter Institute for Caregivers led the training and provided certification in REACH protocols to the interventionists. The certification process for the group leader was a 1-day training followed by a day of role play and critique of role play, while the certification process for the interventionist required 2 days of instruction followed by a third day of role play with critique and review of skills. Preparation included reading through the scripts in the manuals and conducting at least one practice session with a staff member acting as caregiver. The role play sessions were audio recorded and reviewed by the research team to determine whether the candidate would be certified.

In Massachusetts, which trained both adult day staff and ADRC staff, the grant project coordinator did advance planning by surveying day program and home healthcare staff, and ADRC coordinators and program directors, to determine what training content was most needed. Trainings were divided into basic and advanced sessions to accommodate different levels of staff expertise. Basic training covered an overview of the disease, symptoms, diagnosis, and resources available to families; advanced training included case studies and an exploration of strategies for responding to families’ changing needs as the disease progresses.

North Carolina also collected information in advance to ensure that the training program would cover the greatest areas of need. During pretraining interviews, participating physicians were asked about their knowledge and practices and personal experiences with difficult dementia cases so that these topics could be targeted to their specific needs.

In Michigan, the Creating Confident Caregivers (CCC)-VA grant aimed to reach persons with dementia and caregivers who are veterans. During the implementation of this project, AAA staff and trainers became increasingly aware that many veterans hired family or friends to provide their personal care; as paid caregivers, this group was not eligible to participate in the CCC-VA program. At the same time, the Michigan Office of Services to the Aging was implementing a Health Resources and Services Administration training grant to develop and deliver a personal care aide curriculum. A grant modification request was approved to use a small amount of the CCC-VA project's funding to develop an additional half-day dementia training program, based on the Savvy Caregiver Program, for personal care aides.

In Kansas, the Alzheimer's Association chapter provided training on dementia to state mental health staff. Six mental health centers, serving a total of 30 counties, received the "Neuropsychiatric Symptoms of Dementia: A Visual Guide to Response Considerations" training and associated education sessions. Prior to training, mental health staff said they did not see individuals with neuropsychiatric symptoms related to dementia. Post-training, mental health staff agreed that they had seen clients with these problems but had not recognized them.

The Central Missouri AAA, the Missouri Department of Health and Senior Services, and the Missouri Alzheimer's Association Chapters were trained in the use of the AD-8, which is a brief informant interview instrument designed to screen for possible dementia. The AD-8 tool provides a mechanism to determine whether an individual is experiencing any changes in memory, problem-solving abilities, orientation, and daily activities.

In New Hampshire, the Dartmouth Center for Health and Aging conducted a series of educational events on Alzheimer's disease for physicians and other primary care practitioners. The Center led six grand rounds presentations and three lunch-and-learn sessions, covering topics including biological indicators and treatment options for ADRD, diagnostic guidelines, the merits of early screening for ADRD of individuals and their families, ADRD assessment tools, and the role of families and caregivers in assessing for ADRD; a total of 215 healthcare professionals attended.

Infrastructure Development

Long-term services and supports systems can often be fragmented with different areas being managed by various state government agencies and multiple providers. Infrastructure development is important to ensuring good communication among agencies and integration of services. Many grants found ways to link their practices and to make services more efficient or effective, through improved use of technology or alignment of practices.

Georgia adopted the TCARE® protocol to promote better assessment and care planning and improved administrative efficiency. The project used new TCARE®*e* software developed by Rhonda Montgomery, PhD, that allows care managers to enter assessment data into a website and uses those data to create a care consultation worksheet and care plan, and to fill out various state administrative forms. Project staff estimated that this software will cut in half the time that care managers spend on the paper-and-pencil version of the instrument. A database of search terms was also created which links the information found in the state's ESP, an electronic resource database used by care managers, to the TCARE®*e* process. This automates the ability of care managers to recommend appropriate, locally available services to their clients. It streamlines the process so that care managers do not need to go back and forth between two different information systems.

In Missouri, the AAA staff and the Alzheimer's Association chapters used a web-based reporting system through the National Aging Program Information Systems, Missouri's comprehensive, client specific service delivery data tracking system, to input client information and the AD-8 scores into the database. These data were used to then indicate whether a referral was made to the local Chapter.

California's grant involved working with the Kaiser Permanente of San Francisco information technology department to add a dementia care plan to patients' electronic records, including details about all aspects of the patient's assessment and recommended resources for the family. It served as a checklist of issues to be addressed and ensured that there was a written, comprehensive plan relating to caregiver support. When possible, items were populated from other parts of the medical record to reduce data entry and keystroke errors. The care plan went through rigorous testing by nurse case managers and social workers.

In Massachusetts, both ADRCs and the Alzheimer's Association appointed official liaisons to connect the two organizations. ADRCs developed a statewide referral form that will assist in tracking referrals from the Alzheimer's Association and the services offered. At the time of the final grant report, several ADRCs were using the form. In addition, the Massachusetts Executive Office of Elder Affairs and the Massachusetts Rehabilitation Commission are both developing databases for the ADRCs, which will facilitate electronic referrals between ADRC partners. These databases will include the same Alzheimer's disease referral information that is on the referral form.

The Early Stage Dementia Initiative in Minnesota selected local organizations to serve as Memory Care sites; eight such sites were created, with a designated Memory Care Consultant at each site. All eight sites adopted Early Memory Care Guidelines to facilitate identification, diagnosis, care planning, and ongoing support and education. These sites then pursued collaborative relationships with local clinics that had indicated an interest in project participation. All participating clinics adopted at least one component of the clinic guidelines, and one clinic adopted several components. This clinic screened all patients over the age of 70 using the Mini-Cog at routine clinic visits, after which the physician was informed of the results. If appropriate, the physician made a diagnosis and referred the client to the Memory Care Consultant, using a fax referral process.

In Tennessee, the grantee found that partnering with local churches and nonprofits not only resulted in better integration of dementia care services in the community, but also allowed for more cost-effective service delivery because these organizations allowed their facilities to be used for training events at no cost. Partnering with adult day care providers also enabled caregivers to participate in training because respite was available.

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SECTION 2:
PROGRAM OUTCOMES

Program outcomes help to determine the extent to which an intervention has achieved its intended results. Program outcomes for these grants include the number of persons served, participant assessment of the services provided, how the grants changed the delivery of services, and the effect of the interventions on people with dementia and their caregivers.

2.1 Number of People Served

The 60 grants served a total of 28,227 persons, about evenly split between caregivers and persons with dementia. An average of 470 persons were served by each grant. ***Table 1*** provides the total number of persons with dementia and caregivers served by the 11 grant types. Dementia Capable Networks/Systems and Savvy Caregiver were the two program types that served the most people, followed closely by Nursing Home Diversion projects and Early Stage Dementia Programs.

Table 1
Persons Served by Grant Topic

Grant Topic	Persons with Dementia	Caregiver	Total	Average Number Served per Grant
Total	13,571	14,656	28,227	470
Coping with Caregiving	274	274	548	274
Dementia Capable Networks/Systems	3,748	4,479	8,227	588
Early Stage Dementia Programs	1,780	2,053	3,833	274
REACH OUT	273	273	546	273
Nursing Home Diversion	2,558	2,844	5,402	360
NYUCI	455	459	914	305
RDAD	404	404	808	808
REACH II	449	449	898	225
Savvy Caregiver	3,396	3,187	6,583	2,194
Skills2Care	45	45	90	90
STAR-C	189	189	378	378

SOURCE: ADSSP National Resource Center analysis of grantee final reports.

The target number of persons to be served was available for 25 of 60 closed grants. Of the 25 grants, 17 (68%) achieved or exceeded their target. Two grants reached less than 50% of their target, and the remaining six grants reached between 53% and 84% of their target. Target numbers of participants varied widely among grants, ranging from 25 to 1,225 people, and both grants that achieved less than 50% of their goal had targets of nearly 400 persons each. Michigan's Creating Confident Caregivers, with 2,926 persons served, reached over eight times its target. Six grants reached two or more times their targets.

Table 2 presents data on the demographics of persons with dementia and their caregivers who participated in the demonstrations. Almost all of the persons with dementia were aged 60 or older, as were about two-thirds of the caregivers. The persons with dementia were roughly equally men and women, but more than three-quarters of caregivers were women. Just over half of participants lived in urban areas. Spouses and parents made up the vast majority of persons with dementia and spouses and children made up the vast majority of caregivers. Eleven percent of persons with dementia and their caregivers were Hispanic. Nearly 80% of persons with dementia and their caregivers were white, while 11% were Black or African American. Twenty-eight percent of persons with dementia were veterans as were 11% of caregivers.

Table 2
Participant Sociodemographics

Sociodemographic Characteristics	Persons with Dementia, #	Persons with Dementia, %	Care-giver, #	Care-giver, %	Total, #	Total, %
Total	13,571		14,656	100	28,227	100
Age						
Under 60	503	4	4,781	37	5,284	21
60+	12,202	96	8,181	63	20,383	79
Age Missing	671	—	1,668	—	2,339	—
Sex						
Female	7,052	55	10,447	77	17,499	67
Male	5,659	45	3,111	23	8,770	33
Sex Missing	860	—	1,094	—	1,954	—
Geographic Location						
Urban	5,181	52	5,651	55	10,832	54
Rural	4,801	48	4,595	45	9,396	46
Geographic Location Missing	1,598	—	2,240	—	3,838	—
Relationship						
Spouse	4,715	46	5,911	46	10,626	46
Unmarried Partner	67	1	78	1	145	1

(continued)

Table 2 (continued)
Participant Sociodemographics

Sociodemographic Characteristics	Persons with Dementia, #	Persons with Dementia, %	Care-giver, #	Care-giver, %	Total, #	Total, %
Child	162	2	5,431	42	5,593	24
Parent	4,250	42	198	2	4,448	19
Other Relative	715	7	882	7	1,597	7
Nonrelative	315	3	472	4	787	3
Relationship Missing	1,405	—	1,563	—	2,968	—
Ethnicity						
Hispanic or Latino	1,191	10	1,462	11	2,653	11
Not Hispanic or Latino	10,804	90	11,404	89	22,208	89
Ethnicity Missing	1,513	—	1,617	—	3,130	—
Race						
White–Non-Hispanic	9,379	78	9,978	76	19,357	77
White–Hispanic	1,086	9	1,196	9	2,282	9
American Indian or Alaska Native	101	1	120	1	221	1
Asian	184	2	221	2	405	2
Black or African American	1,196	10	1,471	11	2,667	11
Native Hawaiian or Other Pacific Islander	16	0	21	0	37	0
Persons Reporting Some Other Race	64	1	86	1	150	1
Persons Reporting Two or More Races	72	1	81	1	153	1
Race Missing	1,388		1,515		2,903	
Veteran Status						
Veteran	2,100	28	873	11	2,973	19
Nonveteran	5,422	72	7,107	89	12,529	81
Veteran Status Missing	4,016	—	4,507	—	8,523	—

NOTE: Because of discrepancies in grantee data, numbers do not always total correctly. Percentages exclude missing data.

— = Not applicable.

SOURCE: ADSSP National Resource Center analysis of grantee final reports.

2.2 Target Populations Served

A majority of grants reached their target audiences, using a variety of techniques such as outreach events, media coverage, newspaper advertisements, referrals from other organizations, and distribution of brochures throughout the community. Individuals in the early stages of dementia were often recruited through community outreach events and referrals from healthcare professionals, and through media exposure and distribution of brochures and newsletters. Specific racial and ethnic groups were commonly targeted by building relationships with influential individuals or organizations within those communities, by using media specific to those communities, and through outreach events. Recruitment often was not targeted, but instead blanketed large audiences from which eligible clients were then screened.

Grantees' used several outreach strategies. In Colorado, early-stage participants were recruited through referrals from AAAs, service providers, or other agencies in the aging services network; some also contacted the Alzheimer's Association on their own and were recognized by staff as appropriate for early-stage services. All early-stage families who came into contact with the Alzheimer's Association through any of the above routes were asked to participate in the program. The Kansas grant, which served families experiencing neuropsychiatric challenges related to dementia, made 100 outreach visits to the professional community. Several of these audiences, including mental health center staff, geriatric psychiatric inpatient unit social service staff, adult protective services, and long-term care staff, made referrals to the program, but AAA staff were the primary referral source. South Carolina's Focus on Underserved Populations grant reached out to potential African American participants by working with faith-based communities, including the recruitment and training of volunteer family consultants who served as liaisons between their respective churches and ADSSP program staff. The project also worked with physicians to encourage referral of persons newly diagnosed with the disease.

Thirty-seven of 60 grants (62%) reported serving their intended audience or are presumed to have served their intended audience. For the early-stage projects, unless the grant project stated otherwise it is assumed that the persons served were in the early stages of dementia. Eleven of these grants used specific screening tools to ensure that participants met the desired characteristics (such as being at risk of Medicaid spend down or having neuropsychiatric symptoms).

One grant did not reach its target audience. The Arizona grant aimed to reach minority racial groups and those with low income or limited English, but initial recruitment came from existing AAA client databases that did not represent diverse or underserved caregivers.

Moreover, all participants were recruited from the Tucson metro area, which did not have the ethnic diversity of the target areas in rural southern Arizona.

Seventeen grants partially reached their audience. Nine of these grants were able to reach one segment of their target audience but found it difficult to reach other groups. One grant reached its target of Hispanics, but did not provide any data on reaching people in rural settings. Another grant in Tennessee aimed to reach African American and Hispanic audiences. Although 31% of participants were African American, only 2% were Hispanic; the grant project cited cultural and language barriers as the reason for low participation by the Hispanic community. California's NYUCI grant placed a special emphasis on reaching Chinese, Japanese, and Latino caregivers. The project successfully reached Latinos, despite recruitment challenges, but did not reach Chinese or Japanese communities, partly because of cultural barriers. Also, although two partner agencies already worked with these groups, the clientele that they typically served tended to be older and more frail, have more unmet basic needs, and be more socially isolated than this project was designed to address.

Some grants reported difficulty in getting target clients to participate even after potential participants were identified; this was either because of cultural barriers or because of the time or effort required to participate in the program. In California, self-identification as a caregiver was an issue because many family members did not consider themselves caregivers. Caregivers with less education sometimes were overwhelmed or intimidated by the classroom atmosphere. In addition, cultural norms regarding family responsibilities may have prevented some caregivers from participating. In Minnesota, many families did not have time to participate in the family sessions and in North Carolina, the extensive time commitment and length of intervention was a barrier for recruitment of caregivers.

Finally, for five grants it is unclear whether any/all targets were met. These grants targeted either rural and minority groups or those at risk of Medicaid spend-down or nursing home placement. These grants either did not report their results, or their reported numbers do not make clear whether they were successful.

2.3 Outcomes of Evidence-based Interventions and Innovative Programs

ADSSP is a demonstration grant program. As a result, assessing the efficacy and other outcomes of the grants is important, especially whether the interventions are having an impact on the lives of people with dementia and their caregivers. Although Evidence-Based grants are required to conduct an evaluation of the impact of the project on people with dementia or their caregivers, Innovative Practices grants do not have this obligation. Although not required, recognizing the importance of measuring program outcomes, a large majority (78%) of Innovative Practices grants collected data to evaluate the effectiveness of their intervention on participant outcomes.

All grants sought to improve the quality of life for people with dementia and their caregivers, but specific program objectives differed widely across grants. Some grants sought to build better dementia care systems or partnerships, while others focused on increasing service to a particular group of people. Some grants were meant to translate an academically developed intervention to a community setting. As a result, outcomes, evaluation methods, and measures varied greatly across grants.

2.3.1 Evidence-based Grants

Coping with Caregiving—Two Evidence-based Grants in Arizona and Nevada

The goal of the Arizona and Nevada projects was to translate the program tools and strategies of the Coping with Caregiving intervention into a community-based program. Coping with Caregiving is a psychoeducational program for caregivers held weekly for 10 weeks. Caregivers receive instruction and practice in small groups to learn specific cognitive and behavioral skills. These projects translated Coping with Caregiving into a community intervention involving four to five weekly group meetings, homework, and a series of individual "coaching" calls.

An expansion grant making the Arizona grant a statewide initiative is currently active; a subsequent full evaluation of both grants will be included in the final report of the expansion grant. The goal is to improve four primary outcomes demonstrated in the Coping with Caregiving randomized controlled trial: (1) a significant reduction in depressive symptoms of caregivers; (2) an increased use of positive, adaptive coping strategies; (3) a reduction in use of negative coping strategies; and (4) a reduction in negative interactions with others (members of the caregiver's social support network). The final report for the first Arizona Coping with Caregiving grant includes results from post-program participant evaluations, with 82% saying that they benefited a great deal from the program. A large percentage of participants also reported at least some benefit regarding more confidence in dealing with memory problems (100%); making their lives easier (100%); enhancing their ability to care for the care recipient (98%); and improving their care recipients' lives (88%).

To evaluate the Nevada Coping with Caregiving project, telephone assessments were completed for participants at the baseline, at the conclusion of the program (3 months post-enrollment), and at 6 and 12 months post-intervention. Statistically significant improvements were demonstrated in all areas measured, including caregiver depression, caregiver stress, caregiver coping, coping by the person with dementia, caregiver knowledge of caregiving skills, including managing challenging behaviors, caregiver knowledge of available care services, and caregiver satisfaction with received social support. Caregivers also perceived fewer behavior and memory problems for the person with dementia.

New York University Caregiver Intervention (NYUCI)—Three Evidence-based Grants in California, Georgia, and Minnesota

The NYUCI program supports caregivers through an initial caregiver counseling meeting, four family sessions, and a subsequent caregiver counseling meeting, and additional caregiver consultant time for screening, assessment/reassessment, ad hoc calls, e-mail or telephone communication, information and referral, caregiver support group participation, and other support to the caregiver and family. Several outcomes were evaluated across NYUCI projects, including caregiver depression, caregiver burden, caregiver social supports, and management of problem behaviors. Two of the three grants also examined the effect on placement or intent to place in an institution and caregiver health/quality of life. Results across these outcomes were mixed.

California's grant delivered NYUCI in the Greater Los Angeles and San Francisco areas of California, with a special emphasis on diverse populations including Chinese, Japanese, and Latino caregivers. Caregivers were asked to fill out a questionnaire upon enrollment and again at three follow-up periods. Measures of caregiver depression, placement in a nursing facility, caregiver burden, caregiver health, caregiver social supports, and caregiver management of behaviors did not appear to show any sustained change that was significant; however, the grantee's difficulty in obtaining follow-up responses and the resulting small sample size make the impact of the program impossible to determine.

Georgia's NYUCI program was carried out through two AAAs. Caregiver assessments were performed pre- and post-intervention. The program showed statistically significant improvements in measures of caregiver burden, caregiver satisfaction with social network, and the desire to institutionalize for caregivers who were considering institutionalization prior to the intervention. Measures of caregiver depression and health showed improvements but were not statistically significant. The intervention did not reduce the frequency of problem behaviors, and caregivers reported an increase in bother by the behaviors over the period of the intervention.

The NYUCI translation in Minnesota is called Family Memory Care. It has been implemented through three distinct AoA grants. Under this second grant, the intervention was expanded to more regions of the state and more family caregivers were provided services; five sites were added. Assessments were completed at enrollment and again at 4, 8, 12, 18, and 24 months. Of six outcomes reported, five showed statistically significant positive changes. Perceived caregiver depression showed a decrease over time with a small increase at 12 months. Caregiver stress burden also decreased over the 24-month period. The grant also reported improved caregiver reaction to problem behaviors, reduced caregiver burden, and an increase in social network size. Only one item, the problem behaviors of the persons with dementia, did not show improvement.

Reducing Disability in Alzheimer's Disease (RDAD)—One Evidence-based Grant in Ohio

The purpose of this grant was to implement RDAD, a program that provides support and services through an in-home physical exercise program for persons with dementia and behavior modification skills training for family caregivers. The goal of the project was to pilot RDAD in the Alzheimer's Association, Northwest Ohio Chapter's 24-county service area, which it shares with three AAAs, and then expand the program to other regions within Ohio. The participants received 12 one-hour RDAD sessions over a period of 3 months, with monthly follow-up in months 4–6.

Ohio reported one statistically significant improvement, in caregiver knowledge/competence. This item was measured through a combined assessment of items measuring understanding of memory problems, behavior problems, communication strategies, home safety, driving safety, enjoyable activities, dietary concerns, and supportive coping. No changes were found in caregiver depression, caregiver stress, person with dementia depression, caregiver health strain, or caregiver relationship strain/role captivity. One item, person with dementia physical health, showed a small but statistically significant decline. In addition, the project found that too much use of the ABC (Activator, Behavior, Consequence) behavior problem-solving technique or too much use of the exercise component was related to poor outcomes; therefore it should not always be assumed that "more" is always better.

Resources for Enhancing Alzheimer's Caregiver Health II (REACH II)—Four Evidence-based Grants in Florida, Georgia and North Carolina (Two Grants)

REACH II is a 6-month, evidence-based, multicomponent caregiving intervention including in-person meetings and telephone support that targets the well-being of family caregivers. The overall goal of the evidence-based REACH II is to enhance the ability of caregivers to manage depression, stress, and burden; improve caregiver skills for self-care and healthy behaviors; help caregivers make better use of social support networks; reduce risk for care recipients; and increase the capacity for family care at home. All four grants measured changes in caregiver depression and burden, and some grants also measured changes in the intent to place in an institution, functioning of the person with dementia, caregiver health, caregiver satisfaction with social supports, management of challenging behaviors, and risk assessment. Of these measures, only caregiver depression and burden showed statistically significant improvements across all grants. Two grants also reported positive changes in caregiver self-reports of health.

Florida's REACH program evaluation measures were administered at three time points: baseline, 6 months, and 12 months post-intervention. This grant collected data on more variables than any of the other REACH programs, and also reported statistically significant improvements on almost all measures, including caregiver depression, burden, knowledge, use of services, health, satisfaction with social supports, and management of difficult behaviors. Measures that did not show improvement include caregiver quality of life and risk appraisals. The cognitive and functional status of the person with dementia both showed statistically significant decline over the period of assessment.

Georgia REACH was delivered primarily to rural caregivers in the southwestern portion of Georgia. Georgia assessed participants at baseline and at the completion of the 6-month program. Beyond improvements in caregiver depression and stress, Georgia also reported statistically significant improvements in caregiver health. Desire to institutionalize, coping with challenging behaviors, caregiver coping, and caregiver knowledge/competence showed small improvements that were not statistically significant.

The original North Carolina REACH II grant was delivered in 23 counties throughout the state and assessed participants at baseline and at 6 months after the completion of the intervention. It reported statistically significant reductions in caregiver depression, stress, and risk to caregivers and persons with the disease in the domains of health, safety, well-being, and financial management. Caregiver satisfaction with social support showed small but not statistically significant improvements, and severity of challenging behaviors for the person with dementia either stayed the same or decreased, again with no statistical significance.

The second North Carolina grant sought to expand the REACH II program into an additional 21 counties in North Carolina (beyond the original 23 counties) and also modified the REACH II intervention to be less time intensive, reducing home visits from 12 to 6. Beyond decreases in caregiver depression and burden, this grant also reported a significant decrease in caregiver and care recipient risk in domains of health, safety, well-being, and financial management. Measures of caregiver social support and management of difficult behaviors also showed improvements, but no information was provided on statistical significance of these changes.

Savvy Caregiver—Three Evidence-based Grants in California, Maine, and Michigan

Savvy Caregiver is intended to train family caregivers of those with Alzheimer's disease or another dementia. Savvy Caregiver is a 12-hour training program that is usually delivered in 2-hour sessions over a 6-week period. The program focuses on helping caregivers think about their situation objectively and provides them with the knowledge, skills, and attitudes they need to manage stress and carry out the caregiving role effectively. The expected caregiver outcomes include positive impacts on the caregiver's beliefs about caregiving, their reactions to the behavioral symptoms of their care recipient, and their feelings of stress and burden. These outcomes were generally achieved; all three Savvy Caregiver grants reported significant improvements in caregiver depression, knowledge, and measures of coping/burden. Two grants also demonstrated positive results in caregiver's management of challenging behaviors.

The California grant aimed to provide Savvy Caregiver to ethnically diverse, English-speaking audiences. It collected caregiver data at baseline and at 6 and 12 months post-intervention and reported that improvements in caregiver depression, coping, knowledge, and management of behaviors were observed at both the 6- and 12-month assessments.

The Maine grant delivered Savvy Caregiver statewide, including in the many rural areas throughout the state. Outcome measures were collected at baseline, at 5 months, and at 12 months, and like California, improvements in caregiver depression, coping, knowledge, and management of behaviors were observed at both post-assessments. Maine measured several additional domains. It reported improvements at both 5 and 12 months for the following variables: letting other things slide, finding ways to keep the person with dementia busy, caregiver personal gain (inner growth stemming from the caregiving role), management of expectations, management of comparisons (ability to keep the situation in perspective and identify positive aspects of the caregiving role), and caregiver mastery. It reported improvements in caregiver negative mood at 5 months but not at 12 months. Two other items showed no significant change: larger sense of self and illness (ability to gain a broader perspective of care recipient's condition and draw on faith to keep going) and learning about the disease (caregivers showed improvement in a measure of overall competence but not in learning about the disease).

Michigan's Creating Confident Caregivers program delivered Savvy Caregiver training to rural caregivers throughout the state. Caregiver assessments were completed at baseline and again at 6 months post-intervention. Like California and Maine, Michigan reported statistically significant changes in caregiver depression, coping/burden, and knowledge. This grantee did not collect data on management of behaviors as the other two grants did. Michigan did report significant improvements in several other aspects of caregiving, including life satisfaction, exercise, time alone, ability to reduce expectations, reduced effort to try to make sense of the illness, ability to think about life lessons learned through caregiving, and seeing their situation as different from other caregivers.

Skills2Care™—One Evidence-based Grant in New Jersey

New Jersey's ADSSP project is a translation of the Philadelphia REACH evidence-based research—the Home (ESP)—into a direct service intervention. The Skills2Care™ intervention is a home-based program in which occupational therapists help family caregivers manage challenging behaviors of persons with ADRD. This project aimed to increase the capacity of the AAAs to implement the Skills2Care™ intervention by training occupational therapists, who could then support caregivers in developing their own skills in identifying challenges, problem-solving, and creating a plan of action.

New Jersey measured seven participant outcomes, but because of small sample sizes, no results were statistically significant. Improvement, although not significant, was found in caregiver coping, caregiver coping with problem behaviors, slowed rate of functional decline for persons with dementia, caregiver burden associated with functional status of persons with dementia, and caregiver confidence level in dealing with problem behaviors. No change was found in caregiver knowledge/competence. The number of reported problem behaviors increased from baseline to post-intervention, although again, this change was not significant.

STAR-C—One Evidence-based Grant in Oregon

Oregon implemented a translation of the home-based behavioral intervention called STAR-Caregivers (STAR-C), the goal of which is to decrease depression and anxiety in individuals with Alzheimer's disease and their family caregivers. This version of the STAR-C program used case managers to deliver four home visits (rather than eight in the original program), supplemented by six follow-up phone calls. During the home visits, consultants teach caregivers to understand challenging behaviors, problem-solve strategies, and plan pleasant events; they also provide basic information on Alzheimer's disease and community support resources. The goal of the program was to reduce depression and caregiver stress/burden and to reduce the frequency and severity of behavior problems.

Caregiver assessments were done at baseline, 2 months post-intervention, and 6 months post-intervention. The grantee reported that caregiver depression and stress both showed statistically significant improvement at the assessment 2 months post-intervention; there was still improvement at 6 months, but the change was no longer significant. The person with dementia's levels of depression and quality of life both showed significant improvement that was maintained at both assessment times. Caregivers also indicated that their ability to manage behavior challenges improved, and that the improvement was maintained over time at statistically significant levels. The frequency and severity of the behavior challenges themselves were also measured, but the results were not reported. Finally, measures of caregivers' intent to place the person with dementia in an institution showed no impact.

2.3.2 Innovative Practices Grants

Early Stage Dementia Programs—14 Grants

Many of these programs sought to increase access to services and to raise the number of people with dementia and caregivers using services. For example, Alabama found that some of the program participants had received services from other programs at the AAA, but not many had received dementia-specific services. In Nevada, the Telehealth Early Stage Dementia project reported that it improved the relationships between Native American populations and the existing Nevada Alzheimer's care infrastructure, resulting in increased opportunities to provide support to this population.

Eleven grants reported participant outcomes that were measured using pre/post-test or experimental/quasi-experimental evaluation designs. Six grants measured changes in caregiver depression, but only one, Arizona's EPIC project, reported a significant decrease. One project (Minnesota) found a slight increase; the other four grants did not report the significance of findings or did not find significant changes. Minnesota reported reduced burden and stress for caregivers; Florida reported that a majority of participants did *not* experience a decrease in stress. One grant, Colorado, which provided a 6-hour workshop to early-stage dyads, reported an increase in caregiver coping, but only among those who had had previous experience with the Alzheimer's Association, suggesting that these results may not be entirely attributable to the grant program. As part of its programming, Alabama offered community workshops promoting early treatment. Its outcomes included an improvement in knowledge and attitudes about Alzheimer's disease among caregivers and persons with dementia. Two other grants, Arizona's

EPIC project, which delivered a workshop on early-stage issues, and Ohio's ECHO project, which provided cognitive exercises to persons with early-stage dementia, reported improved knowledge of available community services; there was not a related increase in the usage of these community services.

Three early-stage grants measured changes in depression and quality of life for the person with dementia. Two—Arizona's EPIC project and Minnesota's Early Stage Dementia Initiative, which provided medical referrals, individual assessments, and ongoing coaching and education—reported statistically significant improvements in both of these areas, while a third grant, Ohio's ECHO project, reported no improvement. Minnesota also reported improvement in coping by persons with dementia, as did Colorado.

Florida's Healthy Brain Initiative used the MindSet program of cognitive exercises to improve the perceived function of persons with early-stage dementia. This grant measured potential changes in memory and functioning including the perception of memory skills by the person with dementia, perception of memory-related tasks by the caregiver, perception of the person with dementia's functioning in instrumental activities of daily living by the caregiver, and recall using visual and verbal associations. However, at least some of these measures asked participants to rate their own abilities in regard to memory, without testing those abilities directly. Statistical significance of the results was not reported.

Nursing Home Diversion—15 Grants

These grants employed a variety of approaches to help persons with dementia stay in their own homes as long as possible. Interventions included promotion of consumer-directed care respite, other screening and interventions to support caregivers, education and support programs for both those affected by the disease and professionals, efforts to keep persons with dementia active and engaged, and improved coordination among agencies.

Thirteen grants reported participant outcomes that were measured using pre/post-test or experimental/quasi-experimental evaluation designs. Measuring a delay or prevention of nursing home placement is challenging, and only three of the Nursing Home Diversion grants reported their results. Georgia's Caregiver Assessment and Nursing Home Diversion project reported that those caregivers who participated in the TCARE® intervention expressed a decrease in their desire to place, compared to a control group that showed the opposite trend. Because of a small sample size, however, this change was not statistically significant. Tennessee, which aimed to help African American and Hispanic caregivers tap into their own social support networks for respite, monitored placement in a nursing home among its participants: only 1 of the 80 persons with dementia served had a nursing home placement during this grant period, suggesting that the participants may not have been at high risk of institutionalization. Washington's Memory & Wellness Services project, which provided care consultation and respite to caregivers, collected data on caregivers and care receivers at baseline and at 3 and 6 months after baseline and found that relatively few care receivers in any of the study groups were enrolled in Medicaid or used Medicaid-paid long-term care services within 6 months.

Of eight nursing home diversion grants that measured caregiver depression, five grants reported statistically significant decreases in caregiver depression: Michigan's Innovative Creating Confident Caregivers program, which modified Savvy Caregiver for veterans; Maine's Alzheimer's Diversion Initiative, which provided depression screening and intervention for caregivers; Georgia's TCARE program; Texas' Community Stressbusting Program; and Utah's Counseling the Alzheimer's Caregiver programs, all of which provided some form of group support and education to caregivers. The other three grants had mixed results: Washington did not report its results, Missouri reported slightly higher (but not statistically significant) levels of depression, and Virginia reported an initial decrease in depression at 1 week post-intervention that was not maintained 1 month post-intervention.

Nine grants also measured caregiver stress/burden pre- and post-intervention, but only two of those grants, Georgia and Texas, reported significant improvements. Georgia indicated that lower levels of caregiver stress continued to improve over the 9-month intervention, while Texas' measure of caregiver burden showed improvements at the end of the intervention and at 2- and 4-month follow-ups.

Improved ability among caregivers to handle or cope with difficult behaviors was reported by three grants: Maine's Alzheimer's Diversion Initiative, Michigan's Creating Confident Caregivers program, and Washington's Dementia Partnerships project. Washington stated that caregivers in the intervention group had less distress over problem behaviors than those in the comparison group. This improvement was measured with four items on Self-Efficacy Scale prior to starting the program and 5 to 7 weeks after completion in Michigan. Maine did not provide more details on its evaluation. Other statistically significant outcomes included lower levels of caregiver identity discrepancy (Georgia), self-reported caregiver health and life satisfaction (Michigan), and increased feelings of caregiver support and caregiver knowledge (Utah). Two grants, Washington and Missouri, reported decreased depression for the person with dementia.

Dementia-capable Networks/Systems—14 Grants

Dementia-capable Networks/Systems projects focused on enhancing linkages across provider networks and government agencies to improve access to home and community-based services for individuals with Alzheimer's disease or related disorders. Three grants, California, New Mexico, and South Carolina, specifically aimed to build connections with underserved communities—Latino and Vietnamese in the case of California, Latino and Native American in New Mexico, and African American in the South Carolina grant. Two grants, New Mexico and Wisconsin, targeted veterans in need of services. Grants worked to coordinate the processes of awareness, diagnosis, referral, and support through outreach to physicians, community organizations, and persons with the disease.

Five grants reported participant outcomes that were measured using pre/post-test or experimental/quasi-experimental evaluation designs. The project in Kansas proposed a model for dementia integration into state geriatric mental health planning. It provided crisis support to 93 families facing Alzheimer's disease with neuropsychiatric complications by offering information on the disease, advocating for appropriate treatment, bridging communications with physicians and other professionals, aiding in resource acquisition, and counseling family members. In 45 of the 93 cases (48%), neuropsychiatric challenges placed the community-dwelling person at risk of nursing home placement; in 24 of those cases (53%), placement was delayed. The grantee also reported statistically significant decreases in caregiver depression and stress and increases in caregiver knowledge.

Part of California's San Francisco Dementia Care Network Project involved education of persons with dementia and family caregivers and linkage with other resources through the help of a dementia care specialist. The grant reported significant increases in caregiver knowledge as a result, and also increased use of all services that were part of this intervention, including support groups, education, telephone help, case management, and other respite, as reported by caregivers at enrollment and 6 months post-enrollment. Two other grants, California's Innovation Grant to Better Serve People with ADRD, and North Carolina's Strengthening the Linkages Expansion, also reported increases in participants' use of available services, but did not perform a test of statistical significance for these changes. The two grants that measured usage of medical services by persons with dementia found no decrease.

Minnesota's Early Stage Dementia Initiative, which integrated Memory Care Sites with healthcare professionals throughout the state, providing screening, care consultation, and education, measured six participant outcomes: caregiver depression, caregiver stress, caregiver coping, caregiver knowledge/competence, person with dementia depression, and person with dementia quality of life. Because of small sample size, no changes were statistically significant. Person with dementia quality of life and caregiver depression both worsened slightly but not significantly, while the other measures showed small but not significant improvement.

Because grants in this category were often focused on training professionals within the healthcare system and at other community organizations, some outcomes measured pertain not to persons with dementia or their family caregivers, but to other professionals. North Carolina's Strengthening the Linkages program provided formal dementia education to physicians and other healthcare professionals and also worked to address unmet needs for persons in the early stage and their caregivers through collaborative planning with AAAs statewide. It trained 24 primary care physicians, 6 primary care nurse practitioners, and 2 primary care physician assistants in dementia care, and conducted pre/post training evaluations and follow-up interviews, which indicated that the program helped improve physicians' ability to work with persons with dementia and their family caregivers. A survey was also conducted with six key AAA providers, who reported having a better understanding of and response to the needs of people with early-stage dementia and their caregivers; and were better able to provide more resources, education, and information.

The Strengthening the Linkages Expansion grant in North Carolina went on to train an additional 30 primary care physicians in dementia screening, diagnosis, and treatment. Physician interviews and assessments were conducted pre-training and at 6 and 12 months post-training. Physicians reported increased confidence in all identified dementia clinical skills and knowledge areas. Areas showing most improvement were use of medications for memory loss, delivering patient and caregiver education, and referring patients to community resources. Nearly half of the intervention physicians (47%) responded that the training influenced whom they screened for cognitive impairment. The majority of intervention physicians (87%) also reported changes in screening or assessment procedures, including changing the tools they use and involving office staff in their administration. Although not statistically significant, dementia diagnosis rates increased post-training for the intervention group as did use of specific codes and use of the mild cognitive impairment code.

2.3.3 Summary of All Grants

Because grants are testing different—and often brand-new—interventions and using different evaluation measures, it is difficult to compare effectiveness across grants. Moreover, many grantees do not provide outcomes for all of their project goals. For example, many projects listed goals for system improvement, but provided no measures of system improvement. Grant projects provided very different levels of information about their evaluation processes, making it difficult to assess the quality of some of the evaluations.

The grants used a variety of evaluation tools. Eighteen grants asked participants to complete questionnaires at the end of the service period or at the end of each training or intervention session; 14 projects, all Innovative Practices grants, used these questionnaires as their only form of evaluation. Questions typically covered the quality of the materials, satisfaction with the presenter or interventionist, the usefulness of the information or services, and the participant's self-reported changes in attitude, knowledge, or skills. Four grants used similar questionnaires or interviews with program staff.

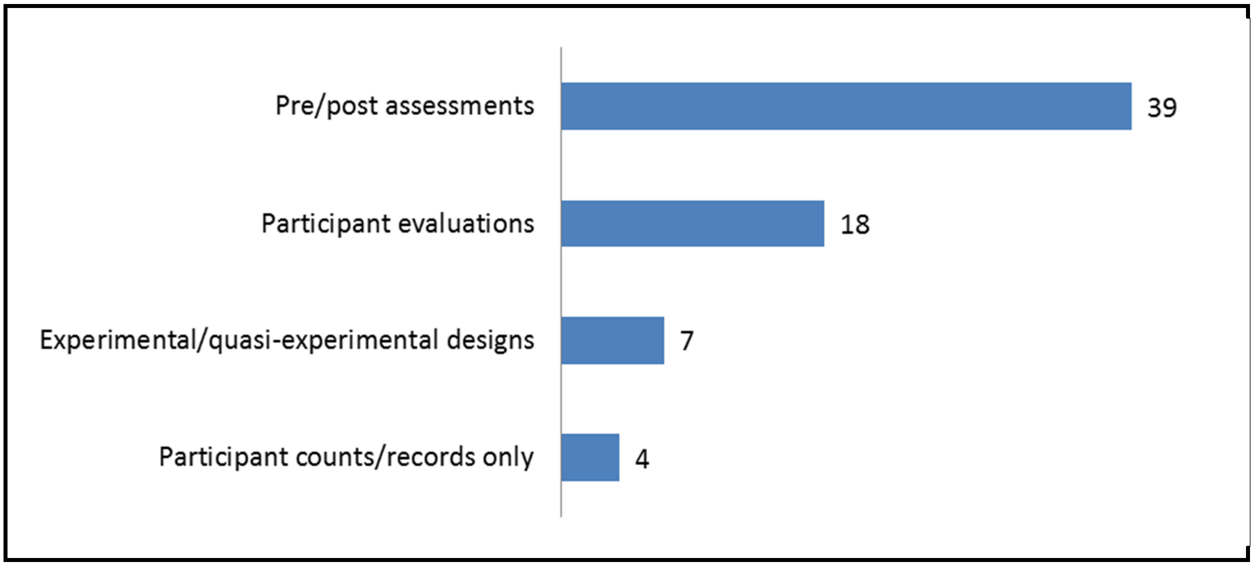
The most common method of evaluation was pre/post assessments that measured participants on one or more variables at the start of the intervention and at predetermined intervals during or at the completion of the program (or, in some cases, several months after the intervention's completion). Thirty-nine grants employed these types of measures aimed at detecting changes resulting from a service or other intervention. Many of these pre/post measures incorporated validated instruments for measuring stress, depression, and quality of life.

In addition, seven grants used experimental or quasi-experimental designs to measure effects of programs. For example, the Georgia Caregiver Assessment and Nursing Home Diversion project screened caregivers for stress and depression; those who scored medium to high on either measure were found eligible for the program and were assigned randomly to a treatment or control group.

Exhibit 5 summarizes the types of evaluation measures used to assess participant outcomes for persons with dementia and caregivers. Numbers add up to more than 60 because some grants used more than one approach.

Overall, there were 43 grants using either pre/post-tests or experimental/quasi-experimental designs to measure outcomes for persons with dementia, caregivers, or both. Thirty of those grants, or 70%, reported statistically significant improvements on at least one measure. There were seven outcomes most commonly seen in assessing improvements: (1) caregiver depression/stress/ burden/coping ability; (2) caregiver overall health; (3) caregiver knowledge/competence regarding dementia and managing challenging behaviors; (4) caregiver knowledge of, use and satisfaction

Exhibit 5.
Number of Grants Using Various Evaluation Methods to Assess Participant Outcomes



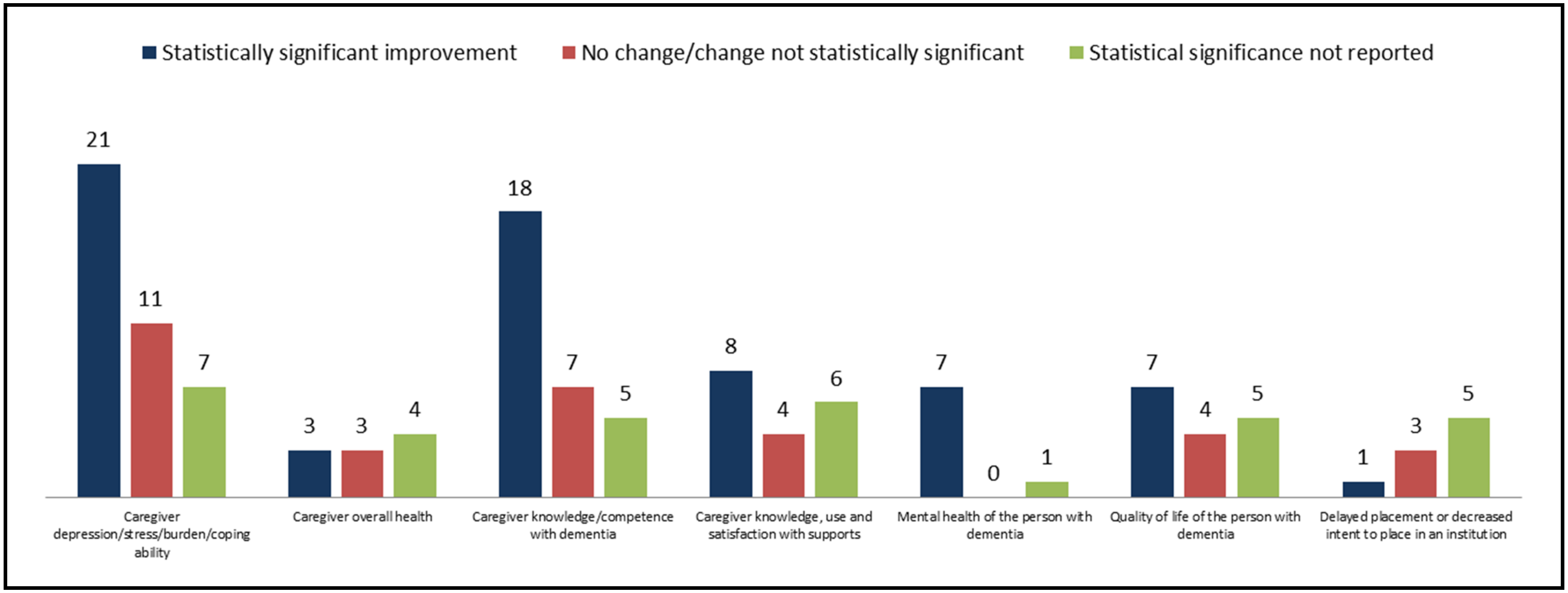
SOURCE: ADSSP National Resource Center analysis of grantee final reports.

Grants used a variety of evaluation tools, the most common of which was assessments conducted both pre- and post-intervention (39 grants). Seven grants used experimental or quasi-experimental to measure program effects; 18 grants asked participants to complete questionnaires at the end of the service period or intervention session. Numbers add up to more than 60 because some grants used more than one approach.

with supports, including community services and personal social support systems; (5) person with dementia mental health; (6) person with dementia quality of life; and (7) delayed/decreased placement or intent to place in a facility.

Exhibit 6 summarizes the quantitative evaluation results from the 43 grants using pre/post-test or experimental/quasi-experimental evaluation designs to measure the seven broad outcomes described above. Of the 39 grants that measured changes in caregiver depression/stress/burden/coping ability, 21 projects reported a statistically significant improvement, 11 reported that changes were not statistically significant, and 7 did not indicate whether changes were statistically significant. Thirty grants measured changes in caregivers' knowledge/competence: 18 showed statistically significant improvement, while 7 showed no statistically significant change and five did not report statistical significance. Eighteen grants examined whether caregivers' knowledge, use of, or satisfaction with available social and community supports had changed; eight of those grants reported a significant improvement, while four reported no change and six did not report statistical details of their findings. Changes in overall caregiver health were measured by 10 grants, with 3 showing statistically significant improvement, 3 showing no statistically significant change, and 4 not reporting statistical

Exhibit 6.
Participant Outcomes among Grants Using Pre/Post Test or Experimental/Quasi-Experimental Evaluation Designs



SOURCE: ADSSP National Resource Center analysis of grantee final reports.

43 grants used pre/post-test or experimental/quasi-experimental evaluation designs to measure seven broad outcomes, including: caregiver depression/stress/burden/coping ability (21/39 grants reported statistically significant improvement); caregiver overall health (3/10 grants reported significant improvement) caregiver knowledge/competence with dementia (18/30 grants reported significant improvement); caregiver knowledge, use and satisfaction with supports (8/18 grants reported significant improvement); mental health of the person with dementia (7/8 grants reported significant improvement); quality of life of the person with dementia (7/16 grants reported significant improvement); delayed placement or decreased intent to place in an institution (1/9 reported significant improvement).

significance. Increased knowledge of or usage of services by caregivers was measured by seven grantees, with two showing statistically significant improvements and five not reporting whether changes were significant. The quality of life for persons with dementia, including various measures of functioning, was evaluated by 16 grants. Seven reported significant improvement, four reported no change, and five did not elaborate on statistical significance. The mental health of persons with dementia, including levels of stress, anger, depression, or general coping, was measured by eight grants, with seven indicating statistically significant improvement and one not reporting results. Finally, nine grants sought to delay/decrease placement in facilities or intent to place in a facility: five did not report the significance of any changes, three indicated that changes were not statistically significant, and one reported statistically significant improvement in this indicator.

In addition to the seven outcomes described above, 27 grants measured other participant outcomes for persons with dementia or caregivers, including such items as identity discrepancy for caregivers (based on preexisting relationship with care recipient), positive and negative emotional affect for caregivers, and use of programs and services by the person with dementia. Of these 27 grants, 11 projects reported statistically significant positive outcomes for these measures.

In addition to outcomes for persons with dementia and their caregivers, some grants also reported on positive outcomes achieved with healthcare professionals and other community service providers. Generally these assessments were not conducted with the same rigor in research design or statistical analysis as those used for the measures discussed above. Four grants reported that healthcare providers trained through this project were better able to identify persons with dementia, and also to support those with dementia. Two grants also reported that among community service providers, the project helped staff attain a greater knowledge of Alzheimer’s disease; one grant reported improving law enforcement personnel’s ability to identify behaviors typical of Alzheimer’s disease patients and improving awareness of wandering and driving safety for persons in the early stages; another grant reported increased job satisfaction among care managers involved in TCARE®.

SECTION 3:
CHALLENGES

In their final reports, grantees report challenges experienced during the planning and implementation of the project. Challenges included marketing and outreach, worker training, infrastructure development, evaluation, and administrative issues, such as personnel changes, delays in establishing service contracts, and delays with Institutional Review Board (IRB) processes.

3.1 Marketing and Outreach

Some grantees experienced difficulty enrolling people into their program. Ten grants reported difficulties recruiting participants from target ethnic groups, especially Hispanics and American Indians. Barriers to participation included cultural norms against asking for help, lack of established trust between the target audience and the organization(s) providing the intervention, language differences, logistical difficulties (e.g., transportation), lower education and literacy levels, lack of self-identification with having dementia or with being a caregiver, and concerns about immigration status. Recruiting rural participants was also challenging for some grantees. Community norms and cultural values, such as strongly held beliefs that families should “take care of their own problems,” affected enrollment. Several grantees commented on the importance of finding staff and other organizations that already have established relationships with the target community. Allowing a substantial amount of time for trust-building and for program promotion activities was identified as an important strategy to overcome these problems.

A few grants encountered resistance to various aspects of the services offered. For example, California’s NYUCI program found that some Chinese caregivers, who had been targeted by this grant, did not continue the program because too much personal information was being asked of them. In New Mexico, awareness of respite care was low among caregivers, and even when publicized, many caregivers were uncomfortable with the idea of leaving their loved ones with strangers.

Recruiting people with early-stage dementia and their caregivers was also challenging; of 20 grants that included early-stage persons as a target audience, 9 reported difficulty reaching this group. One problem involved improper referral of persons who were too far along in the course of the disease to benefit from or be eligible for the program. Based on the reported experience of these grantees, people who are in the early stages of the disease are also often in denial and grappling with the stigma around dementia. Thus, they do not want to participate in programs for people with Alzheimer's disease. One solution was to use language that did not mention Alzheimer's disease or did not necessarily imply that the person requesting information had dementia. For example, North Carolina found that it was more effective to market to "people interested in learning about memory loss," than to "people with early memory loss." Another grant, Missouri's Project LEARN, allowed more moderate-stage people into its program, which may have resulted in lower program completion rates. A third grant, Vermont's REACH OUT, produced a community access television program to increase recruitment.

Physicians' lack of time was identified as a barrier by seven grants, making it difficult to find an opportunity to train them on dementia-related issues or to enlist their help in identifying and referring persons in need of services. Solutions included working with other healthcare staff (such as nurses and social workers) whenever possible, and simplifying the referral process.

A few grantees found that working caregivers' schedules posed a challenge to recruitment and retention. Programs being held during the day were not accessible to this group, so accommodations had to be made. For example, North Carolina's REACH II program scheduled caregiver meetings after work hours, in the evenings or on weekends. One interventionist reported meeting with a caregiver who was a public school teacher during her planning period in the afternoon. These accommodations proved to be successful in enabling more caregivers to participate in the intervention.

Michigan's Creating Confident Caregivers grant, which specifically targeted veterans, indicated that the recruitment of participants was the most discouraging feature of the project. Although the project assumed that VA staff would provide referrals, Health Insurance Portability and Accountability Act confidentiality concerns impeded sharing information with the AAA partners. Even if confidentiality had not been an issue, VA Medical Centers (VAMCs) and the Veteran Directed-Home and Community-Based Services program reported that low numbers of their service recipients had dementia or did not have data on whether they had dementia. VA staff also reported that they had no knowledge if a veteran was a caregiver for a person with dementia. VA physicians were not likely to diagnosis dementia and were unable to share any information about those already diagnosed. In response, AAAs increased their outreach efforts by contacting or seeking support from veterans groups, such as Veterans of Foreign Wars, Paralyzed Veterans of America, and Michigan Military and Veterans Affairs offices. Brochures were modified to cite symptoms, rather than call out a specific diagnosis. Yet when these actions failed to provide sufficient or consistent participants for a program, some of the AAAs withdrew. The modification to allow nonveterans in the CCC-VA programs helped to increase participation, but the regions were still required to ensure that every program had veteran dyads in them.

Wisconsin's program targeted veterans and also had difficulty reaching its intended audience. The grantee discovered that many people do not consider themselves veterans unless they served on active duty, so the language was changed to "Have you ever served in the military?" which resulted in many more people self-identifying as veterans. The assumption that veterans would prefer classes at the VAMC was also incorrect, and the vast majority of classes scheduled at the VAMC had to be cancelled.

3.2 Worker Training

Six grants cited the time involved in training as a significant challenge. In Connecticut, the training and supervision of new staff trainers was time consuming and often delayed the start of scheduled cognitive programs, affecting the testing schedule. The Maine Savvy Caregiver certification process required 46 hours plus travel time; it was hard for agencies to commit staff resources to the process.

A related challenge mentioned by two grants was the difficulty of training staff at many agencies or in geographically dispersed areas with a limited number of master trainers. The Minnesota project minimized travel through the use of technology; for example, video conferences were used for providing large-scale early memory care training, and regular conference calls reinforced the collaborative learning and offered opportunities to identify needed additional training.

Developing trainings that are appropriate for organizations whose staff members have varied experience and education, or who are not already familiar with dementia, was cited as a challenge by two grants. For example, as part of the Massachusetts grant, the Alzheimer's Association provided dementia-related training to AAAs and Independent Living Councils. Although the Alzheimer's Association emphasized safety, the Independent Living Councils emphasized consumer independence and autonomy. This difference in philosophy was addressed through training planning meetings, during which the two networks were able to discuss their differences in perspective. The Alzheimer's Association agreed that acknowledging the importance of self-determination—and discussing the challenges of balancing consumer rights to autonomy with the safety needs of consumers, their families, and the public—would be a valuable component of the training. A trainer was also chosen to deliver the web-based training who had experience in serving both people with Alzheimer's disease and people with disabilities.

Four grants also cited the challenge in finding program staff and trainers with the necessary qualifications. Minnesota has a statewide network of caregiver consultants who work with caregivers of individuals with various diseases and conditions. Some of the Family Memory Care consultants were recruited from among these consultants. Although their generalist caregiver consultant experience provided a solid base, those who did not have a graduate degree in social work or gerontology required significantly more training and clinical support than graduate-level caregiver consultants. This challenge was addressed by providing the required additional training and support, but doing so was time-consuming and costly and delayed the start of recruitment. In Michigan, VA staff were nurses or social workers, many of whom had no group experience or limited knowledge about dementia caregiving. Likewise, some AAA staff had little training experience.

3.3 Administrative Challenges

Grants found infrastructure development difficult because of limited resources and the need to coordinate across a large number of organizations. Changes took longer than expected to facilitate in a number of areas, including coordinating processes among organizations and changing organizational culture and practices. For example, at the outset of Ohio's RDAD program, several challenges arose that required changes within the Alzheimer's Association chapter. Staff responsibilities and workload needed to be redistributed, and chapter staff and volunteers needed to be educated about the purpose of the program. The chapter had to work to procure needed supplies and materials, review chapter policies and procedures to determine whether any changes needed to be made, and examine the impact the program may have on other services and the budget of the chapter. These same issues had to be addressed as each new chapter in Ohio began implementing RDAD.

One of the most common challenges cited by grants was staff turnover. Twenty grants named this as a problem. The North Carolina Linkages program, which provided training to physicians, experienced the departure of the project coordinator and a leave of absence by another key staff member, which caused problems in maintaining the monthly physician newsletter. In New Jersey, the lead researcher left her position during the grant's implementation period.

Several grants faced implementation complications because of budget cuts by the state or other participating organizations. These cuts led to limitations in grant activities and hiring and, in at least one case, impeded recruitment efforts. For example, as a result of state budget cuts, the Massachusetts Executive Office of Elder Affairs focused on minimizing the impact of budget cuts on current programs and consumers rather than developing new programs. Further, budget cuts triggered a state hiring freeze, which delayed hiring a project coordinator. Elder Affairs overcame this challenge by reallocating funds for the project coordinator to the Alzheimer's Association who hired and supervised the project coordinator. In Alabama, state budget cuts of 10% resulted in difficulties securing funds for the required state match. As a result, some services, such as person-centered planning and in-depth case management, were eliminated from the grant program. The budget reductions also necessitated eliminating tasks related to the development of consumer-directed care options.

Delays in service contracts impeded progress for at least two grants. Louisiana reported that processing time for state contracts was extensive, necessitating no-cost extensions for the project. While program administrators were waiting for a response to these no-cost extension requests, operations were shut down at one ADRC because no funds were available. The Oklahoma extension grant reported that its contracts were not implemented in a timely manner, impeding the time available for partners to provide services. Funding and administrative difficulties resulted in no services being provided by the Alzheimer's Association for 3 months.

Travel distances caused difficulties for program participants, staff responsible for coordinating service provision, and for program partners trying to complete site visits and conduct face-to-face meetings. Five grantees mentioned this problem. Limited time and funds for traveling longer distances meant that services and communications were often conducted over the phone or by e-mail.

Technological challenges were mentioned by a few grantees. For example, Vermont's REACH OUT program, which had been intended to serve rural populations throughout the state with the help of teleconferencing, found that limited access to broadband services and wireless connectivity posed difficulty when trying to use project-purchased iPads and FaceTime software for caregiver meetings. The state did look into purchasing service contracts and wireless routers for caregivers, but the management and billing of these contracts was convoluted and ultimately seen as unmanageable. Some caregivers had to be served via in-person meetings instead.

Other challenges included delays related to purchasing policies, organizations dropping out of projects, delays in approval by IRBs, and limited financial resources for respite care that would allow caregivers to participate in programs. In Michigan, AAAs had no prior experience with the ADSSP federal funding and program requirements, so the Office of Services to the Aging had to provide oversight of budgets and cash requests. Some AAA staff working for

Missouri's Project Learn inadvertently entered the caregiver rather than the person with dementia into the database, which led to inaccurate statistics.

3.4 Fidelity

Four grants mentioned specific challenges related to fidelity. Two grants described the time-consuming process of developing fidelity protocols. Minnesota's NYUCI project continuously updated protocols and guidelines as new situations arose and stated that it was difficult to simultaneously develop guidelines while starting the implementation. North Carolina's REACH II project also noted that many resources had to be reviewed, which delayed actual implementation. In Maine's Savvy Caregiver project, new trainers found it difficult to conduct the introductory session within the allotted timeframe. The RDAD grant in Ohio found consistent communication across multiple sites challenging and also reported that the frequency of the training sessions and the required data tracking to be cumbersome.

Other grants experienced challenges in delivering the intervention as designed and with participant attrition. California's NYUCI grant experienced difficulty with caregivers who left the project once they felt their immediate needs had been met, or who wanted to save family meetings for times of crisis. Counselors had to reassure these families that help would be available should future needs arise. Idaho's Building Better Caregivers program also faced participant dropout and registrant no-shows. To address this they began to follow up with participants who missed a session, or who signed up but then did not attend; attendance and completion rates improved as a result. In some cases, caregivers or persons with dementia had mental health issues or previous trauma that needed to be addressed before starting the program, which was often impossible with limited resources. Other caregivers were reluctant to involve their adult children in the intervention because they did not want to be a burden on them or be perceived as criticizing their current level of involvement. Finally, some grants expressed difficulty with delivering consistent program content while trying to address the wide variation in the characteristics, diagnoses, and needs of families.

3.5 Evaluation

Challenges with evaluation of the interventions occurred in several areas including efficient data collection and reporting, designing appropriate evaluation measures, low response rates, and lack of sufficient control group sizes. At least 14 grants reported challenges with collecting data. One grant had to revise its pretest measure because it was too long; another determined that paper data entry was actually more efficient than computerized entry because of lags in the data entry system.

Two other grants struggled with tracking data efficiently and consistently, especially among outside organizations. One of these grants chose to use the existing database of one of its partners to resolve internal data problems. Another grant used the same solution for the training portion of its programs, but indicated that participants in other program activities still had to complete multiple instruments.

Five grants had difficulty obtaining sufficient response rates or participation in post-intervention assessments. With one grant, data from 33% of the caregiver/person with dementia dyads could not be completed because participants had either passed away or had become too physically frail to complete post-testing. Another grantee reported that of 87 participants, only 21 returned the post-survey evaluation, making it difficult to draw conclusions about results.

Three grants struggled to obtain sufficient comparison or control group numbers. In one case, the grantee intended to allow self-selection into the intervention group by participants who agreed to take part in a 6-hour education program; in actuality, all dyads chose to attend the program, so there was no comparison group. Another grant randomly assigned some participants to a control group, but later found out that because of pressure from family members, those participants had been provided with the intervention by assisted living facility staff. In a third case, the hospital that had agreed to provide data for a comparison group permanently postponed its involvement in the project.

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SECTION 4:
SUSTAINABILITY

To ensure that projects continue after the end of grant funding, states must seek funding from public programs, such as Medicare, Medicaid, and the Older Americans Act, as well as private programs, such as foundations, private insurance, or community partners. Of the 60 grants discussed in this report, 52 reported that they would continue at least some parts of their ADSSP programs after the end of their ADSSP grants; 17 grants indicated that their programs would be fully sustained, with 6 supported through ADSSP expansion grants. Louisiana's Medicaid Diversion grant was discontinued because of state budget limitations, Idaho's Building Better Caregivers was discontinued for unspecified reasons, and the status of Utah's Early Stage Cognasium project was not reported.

Ongoing financing has come from a variety of sources: Public funding has provided financial support for 39 grants. Federal funds have supported 20 grants, including 9 new ADSSP grants built on previous efforts and 9 projects that used Older Americans Act funds to continue. State funds have continued to support 25 grants. The Alzheimer's Association has provided funding to support 11 grants, while private foundations have covered some ongoing costs for 10 grants. California's Savvy Caregiver grant obtained nominal financial support from assisted living facilities for the cost of hosting programs at their facilities. Four grants used fee-for-service models to sustain some programming. Many grants have received ongoing funding from more than one source. Provision of services has largely been continued by a combination of state agencies (25 grants) and the Alzheimer's Association (24 grants). A handful of grants have programs that have been continued by other public, nonprofit, or private organizations.

Examples of ADSSP initiatives that were being sustained after the grant ended include California, where the Alzheimer's Association chapters continued Savvy Caregiver trainings with a mix of private and public funds, including support from the Older Americans Act funds, the Alzheimer's Association, private foundations, volunteers, and assisted living facilities. The Northern California Chapter also experimented with a fee-for-service model, where participants would pay for the training. Scholarships were available for those who were unable to pay the fee. The fee did not pay for the total cost of the class; therefore, the chapter used its general funds to cover the balance of the costs. The Weinberg Foundation funded the Dementia Care Network model in three additional areas in California: Los Angeles, San Diego, and Sacramento counties. As of 2010 when the grant ended, the Alzheimer's Association Central Coast Chapter was planning on developing an additional Latino Dementia Care Network in the Oxnard/Camarillo area.

In New Jersey, Harmony for Aging and Adult Services developed SAMS Case Management, a comprehensive integrated case management database system that connects agencies and providers across the state; once the system was created it was to have continued without the need for additional funds. The grantee anticipated that Thomas Jefferson University would continue to support trained occupational therapists through technical assistance and some other resources and that Rutgers University might conduct further research through focus groups with caregivers. South Carolina's Focus on Underserved Populations program was also to be sustained by various partners: local community groups, organizations, and churches were to continue the Self-Help Clubs; trained caregivers through the Dementia Dialogues train-the-trainer program were expected to continue to provide education and outreach in the community. The University of South Carolina was slated to continue offering Dementia Dialogues trainings for caregivers, and the Alzheimer's Association South Carolina chapter planned to replicate and expand the volunteer Family Consultant program.

In Georgia, the Division of Aging Services decided to phase in TCARE® statewide. At the time the grant closed in 2010, the state was involved in aiding with implementation at the AAA level, including (1) revision of state policies of client assessment, care management, and in-home respite; (2) disseminating information about the TCARE® model to AAAs to be used as they developed their area plans; (3) trainings for care managers; (4) creating a work team to provide technical assistance; and (5) building screening and assessment tools into Georgia's data collection and reporting electronic system. In addition, Kansas' grant included bridge coordinators who identified and assisted families facing neuropsychiatric complications of dementia. Two of these coordinators were funded as part of the ADSSP grant. A Kansas legislative proposal to address geriatric mental health issues was passed, which included funding for these care coordinator positions in AAAs across the state.

In Massachusetts, both the ADRC and the Alzheimer's Association appointed official liaisons to improve communications between the two organizations as part of the grant. After the end of the grant, these liaisons continued to facilitate referrals between the two organizations, coordinating cross-trainings, promoting awareness between agencies surrounding events and educational programs, and consulting on options counseling sessions. The Massachusetts Alzheimer's State Plan recommended creation of an Alzheimer's Office within the Executive Office of Elder Affairs, which would build on the activities and relationships initiated by the grant.

SECTION 5:
CONCLUSIONS

The goal of the ADSSP program is to improve the lives of people with Alzheimer's disease and related dementias and their caregivers, especially the long-term services and supports system. As a demonstration program, it translates evidence-based programs and tests innovative approaches to serving people with dementia and their caregivers. This report summarizes the experience of 60 completed grants subsequent to the change of focus in the program in 2008 toward evidence-based and evidence-informed programs. Recently, Systems Integration/Dementia Capability grants seek to ensure access to a sustainable, integrated long-term services and supports system that is capable of meeting the needs of persons with dementia and their caregivers to help them remain independent and healthy in the community. As of September 2014, none of those grants have completed their work.

5.1 Grant Descriptions

These 60 completed grants, including 45 Innovative Practices and 15 Evidence-Based grants, were initially funded in 2007–2010. Innovative Practices grants use a variety of approaches to improving the delivery of supportive services at the community level to people with Alzheimer's disease and related diseases and their family caregivers. These approaches have some foundation in research, but have not been rigorously tested in randomized clinical trials. The 45 Innovative Practices grants addressed people with early-stage dementia, nursing home diversion, making long-term services and supports systems dementia capable, and supporting caregivers. Evidence-Based grants translate interventions that have been tested in randomized-controlled clinical trials with the results published in peer-reviewed journals to community settings. The 15 evidence-based grants translated to community settings were Coping with Caregiving, NYUCI, RDAD, REACH II, Savvy Caregiver, Skills2Care, and STAR-C.

The grants addressed a wide range of topics, but the vast majority of the grants focused on outreach and services to those in the early stages of dementia and their families, creation and enhancement of dementia care networks, or helping persons with dementia avoid nursing home placement. Across all types of grants, some of the most common project activities included educating professionals on dementia and service provision, care consultation, education for persons with dementia and caregivers, expansion/enhancement of referral and service networks, outreach events, respite/adult day care, training of physicians and other healthcare professionals, support groups, and screening for dementia. Most grants involved partnerships among state agencies, AAAs, the Alzheimer's Association, and universities.

5.2 Program Outcomes

The 60 ADSSP grants included in this report served 28,227 people over the course of their grant period, including 13,571 persons with dementia and 14,656 caregivers. Savvy Caregiver, Dementia Capable Networks/Systems, Early Stage Dementia Programs, and Nursing Home Diversion projects served the most persons overall. The Savvy Caregiver program averaged by far the highest number of persons served per grant.

Almost all of the persons with dementia were aged 60 or older, as were about two-thirds of the caregivers. The persons with dementia were roughly equally men and women, but more than three-quarters of caregivers were women. Just over half of participants lived in urban areas. Spouses and parents made up the vast majority of persons with dementia and spouses and children made up the vast majority of caregivers. Eleven percent of persons with dementia and their caregivers were Hispanic. Nearly 80% of persons with dementia and their caregivers were white, while 11% were Black or African American. Twenty-eight percent of persons with dementia were veterans as were 11% of caregivers.

All grants sought to improve the quality of life for people with dementia and their caregivers, but specific program objectives differed widely across grants. Although Evidence-Based grants are required to conduct a formal evaluation, Innovative Practices grants are not required to conduct an evaluation, although many did assess the impact of their intervention.

Quantitative data on outcomes are available for 43 grants using pre/post-tests or experimental/quasi-experimental evaluation designs; 30 of those grants reported statistically significant improvements on at least one participant measure. In 21 projects, the grantees reported improved caregiver depression/stress/burden/coping ability. Eighteen grants reported improved caregiver knowledge/competence; eight grants reported improved caregiver knowledge, use, or satisfaction with supports; and three grants reported improved caregiver health. Seven grants measured positive changes in the mental health of persons with dementia, and seven reported improvements in quality of life for persons with dementia. One grantee reported a decrease in intent to place in a facility.

Outcomes for the 11 topic areas included the following:

- *Coping with Caregiving:* Nevada's Coping with Caregiving project employed assessments at baseline and several points post-intervention. Statistically significant improvements were demonstrated in all areas measured, including caregiver depression, caregiver stress, caregiver coping, coping by the person with dementia, caregiver knowledge of caregiving skills, including managing challenging behaviors, caregiver knowledge of available care services, and caregiver satisfaction with received social support. Caregivers also perceived fewer behavior and memory problems for the person with dementia. Arizona used only a post-intervention survey to measure results and reported *at least some benefit* to caregiver knowledge and competence and quality of life for both caregivers and persons with dementia.

- *NYUCI:* Three grants in California, Georgia, and Minnesota measured changes in caregiver depression, caregiver burden, caregiver social supports, and management of problem behaviors. Two of the three grants also examined the effect on placement or intent to place in an institution and caregiver health/quality of life. California's low response rates on follow-up made it impossible to determine any significant changes. Georgia's grant showed significant improvements in caregiver burden, caregiver satisfaction with social network, and the desire to institutionalize for caregivers who were considering institutionalization prior to the intervention. In Minnesota, five of six outcomes showed statistically significant positive changes: perceived caregiver depression decreased over time with a small uptick at 12 months. Caregiver stress burden also decreased over the 24-month period. The grant also reported improved caregiver reaction to problem behaviors, reduced caregiver burden, and an increase in social network size. Only one item, the problem behaviors of the persons with dementia, did not show improvement.

- *RDAD:* Ohio reported one statistically significant improvement, in caregiver knowledge/competence. No changes were found in caregiver depression, caregiver stress, person with dementia depression, caregiver health strain, or caregiver relationship strain/role captivity. One item, person with dementia physical health, showed a small but statistically significant decline.

- *REACH II:* All four grants in this category measured and showed significant improvements in caregiver depression and burden. Two grants, Georgia and Florida, reported positive changes in caregiver self-reports of health. Florida also reported improvements in several other measures, including caregiver knowledge, use of services, social support, and management of challenging behaviors as well as the functional status of the person with dementia.

- *Savvy Caregiver:* All three grants that delivered Savvy Caregiver reported statistically significant reductions in caregiver depression and increases in caregiver knowledge/competence. California also reported improved coping by caregivers and management of challenging behaviors. Maine measured multiple additional items. It reported improvements in directing behaviors, letting other things slide, finding ways to keep the person with dementia busy, caregiver personal gain, management of expectations, management of comparisons, caregiver mastery, and reactions to disruptive behaviors. Michigan reported several significant improvements for caregivers, including burden, life satisfaction, amount of exercise, amount of time alone, ability to reduce expectations, effort to make sense of the illness, ability to think about life lessons learned as a caregiver, and seeing that their situation is different from other caregivers.

- *Skills2Care™:* New Jersey measured seven participant outcomes; perhaps because of small sample sizes, no results were statistically significant. Improvement, although not statistically significant, was found in caregiver coping, caregiver coping with problem behaviors, slowed rate of functional decline for persons with dementia, caregiver burden associated with functional status of persons with dementia, and caregiver confidence level in dealing with problem behaviors. The number of reported problem behaviors increased from baseline to post-intervention but again the change was not significant.

- *STAR-C:* Oregon reported that caregiver depression and stress both showed statistically significant improvement at the assessment 2 months post-intervention; there was still improvement at 6 months, but the change was no longer significant. The person with dementia's levels of depression and quality of life both showed significant improvement that was maintained at both assessment times. Caregivers also indicated that their ability to manage behavior challenges improved, and that the improvement was maintained over time at statistically significant levels. The frequency and severity of the behavior challenges themselves were also measured, but the results were not reported. Finally, measures of caregivers' intent to place the person with dementia in an institution showed no impact.

- *Early-stage dementia programs:* Two grants reported improved caregiver knowledge/competence (Alabama, Georgia); two grants reported increased knowledge or use of services (Arizona, Ohio); and two grants reported improved coping by persons with dementia (Colorado, Minnesota). Decreases in caregiver depression, caregiver stress, and improved coping by caregivers were reported by one grant each (Arizona, Minnesota, and Colorado, respectively). Additionally, two grants, Arizona and Minnesota, reported decreased depression and improved quality of life for persons with dementia.

- *Nursing home diversion programs:* None of the 10 grants in this category reported statistically significant decreases in placements in a facility (grantees measured this change mostly through participant surveys or pre/post assessments; sample sizes were either too small to show any difference or statistical results were not provided). Of eight nursing home diversion grants that measured caregiver depression, five grants reported statistically significant decreases in caregiver depression: Michigan's Creating Confident Caregivers program, Maine's Alzheimer's Diversion Initiative, Georgia's TCARE program, Texas' Community Stressbusting Program, and Utah's Counseling the Alzheimer's Caregiver programs. Nine grants also measured caregiver stress/burden pre- and post-intervention, but only two of those grants, Georgia and Texas, reported significant improvements. Georgia also indicated lower levels of caregiver stress, which continued to improve over the 9-month intervention, while Texas' measure of caregiver burden showed improvements at the end of the intervention and at 2- and 4-month follow-ups. Improved ability among caregivers to handle or cope with difficult behaviors was reported by three grants: Maine, Michigan, and Washington. Other statistically significant outcomes included lower levels of caregiver identity discrepancy (Georgia), self-reported caregiver health and life satisfaction (Michigan), and increased feelings of caregiver support and caregiver knowledge (Utah). Two grants, Washington and Missouri, reported decreased depression for the person with dementia.

- *Dementia-capable networks/systems:* Because these grants were focused on systems rather than individual-level change, many of the grants in this category did not measure participant outcomes. In Kansas, 45 of the 93 persons with dementia were at risk for nursing home placement because of neuropsychiatric challenges; in 53% of those cases, placement was delayed. The grantee also reported statistically significant decreases in caregiver depression and stress, and increases in caregiver knowledge. California's San Francisco Dementia Care Network Project reported that significant increases in caregiver knowledge also increased use of all services that were part of this intervention. Two other grants, California's Innovation Grant to Better Serve People with ADRD and North Carolina's Strengthening the Linkages Expansion, also reported increases in participants' use of available services, but did not perform a test of statistical significance for these changes. North Carolina's Strengthening the Linkages program reported improving physicians' ability to work with persons with dementia and their family caregivers and helping AAA providers better understand and respond to the needs of people with early-stage dementia and their caregivers. In the subsequent expansion grant in North Carolina, physicians reported increased confidence in clinical skills and knowledge pertaining to dementia, and also reported changes in their screening practices.

- *REACH OUT:* The two grants in this category measured participant outcomes pre- and post-intervention, but details on their evaluation processes and results are limited. Puerto Rico does not indicate any statistically significant changes in participant outcomes, although it does say that caregivers reported improved coping, knowledge and health. Vermont reports that changes in caregiver stress and burden were statistically significant.

5.2.1 Challenges

Grant projects faced several challenges in implementing their grants, especially regarding marketing and recruitment, worker training, and administrative requirements. Grant projects used a variety of strategies to overcome these challenges.

- *Marketing and outreach:* Some grant projects experienced difficulty enrolling people for their program, especially racial and ethnic minorities and people with early-stage dementia.

- *Worker training:* Six grants cited the time involved in training as a significant challenge. A related challenge mentioned by two grantees was the difficulty of training staff at many agencies or in geographically dispersed areas with a limited number of master trainers.

- *Administrative challenges:* Grants found infrastructure development difficult because of limited resources and the need to coordinate across a large number of organizations. Common challenges cited by grantees included staff turnover, state budget cuts, delays in service contracts, and travel distances.

5.2.2 Sustainability

To ensure that projects continue after the end of grant funding, states must leverage public funding, such as Medicare, Medicaid, and the Older Americans Act, and private funding, such as foundations, private insurance, or community partners. Existing partners must agree to maintain service provision or must identify new partners to continue the programming. Of the 60 grants discussed in this report, 52 will continue at least some parts of their programs after the end of their ADSSP grants; 17 grants indicate that their programs will be fully sustained, with 6 supported through ADSSP expansion grants.

5.2.3 Future Reports

To have a cumulative record of the ADSSP program, this report will be updated in 2015 as additional grants are completed.

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APPENDIX A
LIST OF COMPLETED GRANTS

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Table A-1
List of Completed Grants

State	Category	Grantee Organization/Agency	Grant Type	Original Period of Performance	New End Date
AL	Early Stage Program	Alabama Department of Senior Services	Innovation	9/30/2008–3/3/2010	3/31/2011
AZ	Coping with Caregiving		Evidence-based	9/30/2008–9/29/2011	9/29/2011
AZ	Early Stage Program	Arizona Division of Aging and Adult Services	Innovation	9/30/2009–3/31/2011	9/30/2012
CA	Savvy Caregiver		Evidence-based	9/30/2008–9/29/2011	9/29/2011
CA	Dementia Capable Systems	State of California, Department of Aging	Innovation	9/30/2008–6/30/2010	6/30/2010
CA	NYUCI	State of California, Department of Aging	Evidence-based	9/30/2009–9/29/2012	6/30/2013
CA	Dementia Capable Systems	University of California San Francisco	Innovation	9/1/2010–8/31/2012	8/31/2013
CO	Early Stage Program	Colorado State University	Innovation	9/1/2010–8/31/2012	9/30/2012
CT	Nursing Home Diversion	State of Connecticut Department of Social Services	Innovation	9/1/2010–8/31/2012	11/30/2012
FL	REACH II	Florida Department of Elder Affairs	Evidence-based	9/30/2008–9/29/2011	3/31/2013
FL	Early Stage Program	Florida Department of Elder Affairs	Innovation	9/1/2010–8/31/2012	2/28/2013
GA	REACH II	Georgia Division of Aging Services	Evidence-based	9/30/2008–9/29/2011	3/31/2012
GA	Nursing Home Diversion	Georgia Department of Human Resources	Innovation	9/30/2008–3/31/2010	12/31/2010
GA	Early Stage Program	Georgia Division of Aging Services	Innovation	9/1/2010–8/31/2012	1/31/2013
GA	NYUCI	Rosalynn Carter Institute for Caregiving	Evidence-based	9/30/2009–9/29/2012	5/31/2013
ID	Nursing Home Diversion	Idaho Commission on Aging	Innovation	9/1/2010–8/31/2012	8/30/2013
IN	Nursing Home Diversion	Family and Social Services Administration	Innovation	9/30/2008–3/31/2010	3/31/2011
KS	Dementia Capable Systems	Kansas Department on Aging	Innovation	9/30/2009–3/31/2011	3/31/2011
LA	Nursing Home Diversion	Louisiana’s Governor’s Office of Elderly Affairs	Innovation	9/30/2008–3/31/2010	12/31/2010

(continued)

Table A-1 (continued)
List of Completed Grants

State	Category	Grantee Organization/Agency	Grant Type	Original Period of Performance	New End Date
MA	Nursing Home Diversion	Commonwealth of MA, Executive Office of Elder Affairs	Innovation	9/30/2008–3/31/2010	3/31/2011
ME	Savvy Caregiver	Maine Office of Aging and Disability Services	Evidence-based	9/30/2008–9/29/2011	9/29/2011
ME	Nursing Home Diversion	Office of Elder Services—ME DHHS	Innovation	9/30/2008–3/31/2010	6/30/2010
ME	Dementia Capable Systems	Maine Office of Aging and Disability Services	Innovation	9/1/2009–2/28/2012	2/28/2012
MI	Nursing Home Diversion	Michigan Office of Services to the Aging	Innovation	9/30/2009–9/30/2011	9/29/2012
MI	Savvy Caregiver	Michigan Office of Services to the Aging	Evidence-based	9/30/2008–9/29/2011	9/29/2013
MN	NYUCI	Minnesota Board on Aging	Evidence-based	9/30/2008–9/29/2011	9/29/2012
MN	Early Stage Program	Minnesota Board on Aging	Innovation	9/30/2008–3/31/2010	3/31/2010
MN	Dementia Capable Systems	Minnesota Board on Aging	Innovation	9/30/2009–3/31/2012	3/31/2012
MO	Early Stage Program	State of Missouri	Innovation	9/30/2008–3/31/2010	6/30/2010
MO	Nursing Home Diversion	Missouri Department of Health and Senior Services	Innovation	9/1/2010–8/31/2012	8/31/2013
NC	REACH II	North Carolina Division of Aging and Adult Services	Evidence-based	9/30/2008–9/29/2011	9/29/2012
NC	Dementia Capable Systems	The University of North Carolina at Chapel Hill	Innovation	9/30/2008–3/31/2010	12/31/2010
NC	REACH II	North Carolina Division of Aging and Adult Services	Evidence-based	9/1/2010–8/31/2013	2/28/2014
NC	Dementia Capable Systems	University of North Carolina, Chapel Hill	Innovation	9/1/2010–8/31/2012	8/31/2013
NH	Dementia Capable Systems		Innovation	9/30/2009–9/30/2011	9/30/2011
NJ	Skills2Care	New Jersey Department of Health and Senior Services	Evidence-based	9/30/2007–3/31/2012	3/31/2012
NM	Dementia Capable Systems	New Mexico Aging and Long-Term Services Department	Innovation	9/1/2010–8/31/2012	8/31/2013
NV	Early Stage Program	State of Nevada Division for Aging Services	Innovation	9/30/2008–3/31/2010	3/31/2010

(continued)

Table A-1 (continued)
List of Completed Grants

State	Category	Grantee Organization/Agency	Grant Type	Original Period of Performance	New End Date
NV	Coping with Caregiving	State of Nevada—Aging and Disability Services Division	Evidence-based	9/30/2009–9/29/2012	9/29/2013
OH	RDAD	Ohio Department of Aging	Evidence-based	9/30/2008–9/29/2011	3/31/2012
OH	Early Stage Program		Innovation	9/30/2008–9/30/2011	9/30/2011
OK	Early Stage Program	Oklahoma Department of Human Services	Innovation	9/30/2008–3/31/2010	11/30/2010
OK	Early Stage Program		Innovation	9/30/2009–9/30/2011	9/30/2011
OR	STAR-C	Oregon Department of Human Services, Seniors and People with Disabilities Division	Evidence-based	9/30/2009–9/29/2012	6/30/2013
PR	REACH Out	Puerto Rico Office of the Ombudsman for Pension Persons and People with Disabilities Division	Innovation	9/1/2010–8/31/2012	3/31/2013
RI	Early Stage Program	Rhode Island Department of Elderly Affairs	Innovation	9/30/2008–3/31/2010	3/31/2011
SC	Dementia Capable Systems	Lt. Governor’s Office on Aging	Innovation	9/30/2008–3/31/2010	9/30/2010
SC	Dementia Capable Systems	South Carolina Lieutenant Governor’s Office on Aging	Innovation	9/1/2010–8/31/2012	8/31/2013
TN	Nursing Home Diversion	Tennessee Commission on Aging and Disability	Innovation	9/30/2008–3/31/2010	6/30/2010
TN	Dementia Capable Systems	Tennessee Commission on Aging and Disability	Innovation	9/1/2010–8/31/2012	8/31/2013
TX	Nursing Home Diversion	University of Texas Health Science Center at San Antonio	Innovation	9/1/2010–8/31/2012	5/31/2013
UT	Early Stage Program	Utah State Department of Human Services	Innovation	9/30/2008–3/31/2010	3/31/2010
UT	Nursing Home Diversion	Utah State Department of Human Services	Innovation	9/30/2009–3/31/2011	3/31/2011
UT	Nursing Home Diversion	Utah Division of Aging and Adult Services	Innovation	9/1/2010–8/31/2012	8/31/2013
VA	Early Stage Program	VIRGINIA DEPARTMENT FOR THE AGING	Innovation	9/30/2008–3/31/2010	2/28/2011
VA	Nursing Home Diversion	Virginia Department for Aging and Rehabilitative Services	Innovation	9/1/2010–8/31/2012	7/31/2013

(continued)

Table A-1 (continued)
List of Completed Grants

State	Category	Grantee Organization/Agency	Grant Type	Original Period of Performance	New End Date
VT	REACH Out	Vermont Department of Disabilities, Aging and Independent Living	Innovation	9/1/2010–8/31/2012	8/31/2013
WA	Nursing Home Diversion	Washington State Social and Health Services	Innovation	9/30/2008–3/31/2010	3/31/2011
WI	Dementia Capable Systems		Innovation	9/30/2009–3/31/2012	3/31/2012
WI	Dementia Capable Systems	Wisconsin Department of Health Services' Bureau of Aging and Disability Resources	Innovation	9/1/2010–8/31/2012	8/31/2013

APPENDIX B
CASE STUDIES OF TEN GRANTS

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Evidence-Based Grant:
Arizona CarePRO

Introduction

The goal of the Arizona CarePro project was to translate program tools and strategies from the evidence-based Coping with Caregiving psychoeducational group intervention into a community-based program, Care Partners Reaching Out (CarePRO) (previously known as REACH Out). The Arizona Department of Economic Security, Division of Aging and Adult Services coordinated the overall activities related to the training and startup of the project. The intervention was implemented in Pima County and the Tucson area by the Alzheimer Association Desert Southwest Chapter's regional office in Tucson, and a local Area Agency on Aging (AAA), the Pima Council on Aging, provided respite and helped with outreach and recruitment of participants. The target population included caregivers who experience barriers to care because of race, ethnicity, limited English proficiency, and other socioeconomic challenges.

The CarePRO project had three main components:

- *CarePRO workshops*—small group meetings or workshops with family caregivers that met for 2.5 hours each week for 4 weeks. The key components of the workshops were stress management, behavior problem management, communication skills, mood management strategies, and basic education about dementia and caregiving.

- *CarePRO Homework*—to reinforce CarePRO workshops, caregivers were given homework or home practice of skills.

- *Caregiver Coach Calls*—caregivers received individual telephone calls to reinforce and review CarePRO workshop skills, overcome barriers to skill practice in the home setting, and tailor aspects of the intervention to meet their particular needs. Calls also served as an opportunity to identify caregivers in need of additional care consultation or referral to other direct services.

The content for the CarePRO workshops' leader manual and participant manual was based primarily on previous materials from the original Coping with Caregiving intervention. Although the CarePRO manuals have been modified from the original randomized control trial trainings/manuals, the new materials include the core elements of the evidence-based Coping with Caregiving intervention.

Outcomes of Intervention Program

Sixty people with dementia and 60 caregivers were served through the Arizona CarePRO project. Sociodemographic characteristics of the participants are summarized in ***Table B-1.***

Table B-1
Sociodemographic Data on Participants in the Arizona CarePRO Project

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Total	60	100	60	100	120	100
Age						
Under 60	1	2	19	32	20	17
60+	59	98	41	68	100	83
Age Missing	0	—	0	—	0	—
Gender						
Female	25	42	49	83	74	63
Male	34	58	10	17	44	37
Gender Missing	1	—	1	—	2	—
Geographic Location						
Urban	42	70	44	73	86	72
Rural	18	30	16	27	34	28
Geographic Location Missing	0	—	0	—	0	—
Relationship						
Spouse	32	54	32	54	64	54
Unmarried Partner	0	0	0	0	0	0
Child	25	42	25	42	50	42
Parent	0	0	0	0	0	0
Other Relative	1	2	1	2	2	2
Non-relative	1	2	1	2	2	2
Relationship Missing	1	—	1	—	2	—
Ethnicity						
Hispanic or Latino	4	7	5	8	9	8
Not Hispanic or Latino	56	93	55	92	111	93
Ethnicity Missing	0	—	0	—	0	—
Race						
White—Non-Hispanic	51	91	35	58	86	74
White—Hispanic	0	0	13	22	13	11
American Indian or Alaska Native	1	2	1	2	2	2
Asian	0	0	1	2	1	1

(continued)

Table B-1 (continued)
Sociodemographic Data on Participants in the Arizona CarePRO Project

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Black or African American	1	2	2	3	3	3
Native Hawaiian or Other Pacific Islander	0	0	2	3	2	2
Persons Reporting Some Other Race	2	4	6	10	8	7
Persons Reporting 2 or More Races	1	2	0	0	1	1
Race Missing	4	—	0	—	4	—
Veteran Status						
Veteran	3	23	2	15	5	19
Non-Veteran	10	77	11	85	21	81
Veteran Status Missing	47	—	47	—	94	—

— Not available or not applicable.

The Arizona CarePRO project has been expanded statewide through an additional Alzheimer’s Disease Supportive Services Program (ADSSP) grant; therefore, a broader, more comprehensive report of outcomes will be included in the subsequent grant report. However, initial outcome measures indicate that caregivers participating in CarePRO workshops have been empowered with new skills and approaches to help them cope with the stressors and burdens of their caregiving roles. Highlights reported include the following:

- All participants who completed the post-evaluation questions reported that they benefited from participating in CarePRO, and 81.6% reported that they benefited a great deal.
- The areas of benefits with the largest proportions of participants reporting a great deal of benefit included understanding memory loss and its effects, confidence in dealing with memory problems, and enhanced ability to care for care recipient. The lowest beneficial impact of the project related to helping caregivers keep their care recipient living at home.
- Additional outcomes related to the training of staff and volunteers (those involved directly with the project and individuals in the community, such as a local support group facilitators) included the following:
  - Interventionists reported that the new knowledge and skills (related to dementia and behavior change, management of stress, mood and behavior problems) they learned and practiced for CarePRO were also applicable to their everyday work as family care consultants.

  - Community partners reported that the CarePRO awareness and orientation training alerted them to specialized trainings that could help caregivers who reported problems with stress or behavioral problems related to dementia.

The full evaluation of both ADSSP grants will address the four primary outcomes demonstrated in the REACH Coping with Caregiving randomized control trial: (1) depressive symptoms of caregivers, (2) adaptive coping strategies, (3) coping strategies, and (4) interactions with others (members of the caregiver's social support network). Additional secondary outcomes identified as important by caregivers and community partners will also be reported in the ensuing ADSSP grant's final report.

Infrastructure Development

As a result of the CarePRO project, the Pima Council on Aging is able to more readily refer families to appropriate services and supports related to Alzheimer's disease and related dementias (ADRD). Similarly, families who contact the Alzheimer's Association Desert Southwest Chapter are more likely to be connected to community partners for appropriate services and supports. Furthermore, the State Unit on Aging has developed partnerships with CarePRO and enhanced referral networks needed to create access for diverse and underserved families.

A total of five staff from the Alzheimer's Association Desert Southwest Chapter were trained to deliver the intervention, with an additional two trained as backup. However, there was significant staff turnover at the chapter, which affected intervention delivery, and also at the local AAA, which affected respite care and other supportive activities. Each staff transition required retraining on the intervention and the intervention philosophy. Also, there was a difference in skills and training between the staff of the original Coping with Caregiving randomized control trial compared with the CarePRO project Alzheimer's Association Chapter staff.

Sustainability

The Alzheimer's Association Desert Southwest Chapter is committed to offering CarePRO beyond the end of the grant throughout the entire chapter area, which covers all of Arizona and Southern Nevada. The chapter will use its normal operating budgets to support CarePRO as ongoing programming.

The CarePRO project director is also the coordinator for the Arizona Family Caregiver Support Program and has encouraged AAAs to use Older Americans Act Title III-E funds and other resources to support evidence-based programs like CarePRO. The AAAs have conducted significant outreach statewide related to ADRD and are reviewing options for offering respite to CarePRO participants who need respite services. CarePRO will continue to operate in Tucson and Southern Arizona as part of the overall project through the second CarePRO ADSSP grant, and Arizona State University is exploring the options that would allow replication of CarePRO.

Lessons Learned and Recommendations for Future Efforts

The participants were recruited through existing client databases, which presented two main challenges:

- The CarePRO project's objective to serve diverse and underserved caregivers was not met because the existing client databases did not aim to be diverse or represent the underserved. This was further complicated by the fact that all participants were recruited from the Tucson metro area. Future recruitment will be targeted to rural areas of Southern Arizona, which should provide a more diverse recruitment base.

- Organizations wanted to retain ownership of their clients, creating communication challenges that hindered the recruitment process. Future efforts will be made to minimize the competition regarding clients, funding streams, and in-kind contributions.

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Evidence-Based Grant: California's Evidence-Based Intervention Grant to Better Serve People With Alzheimer's Disease

Introduction

California's Evidence-Based Intervention Grant to Better Serve People with Alzheimer's Disease implemented and evaluated the impact of the Savvy Caregiver program on English-speaking, ethnically diverse populations across California, including African Americans, Asian/Pacific Islanders, and Latinos. The Savvy Caregiver program is a psychoeducational program for family caregivers of older adults with Alzheimer's disease and other dementias, which provides caregivers with the basic knowledge, skills, and attitudes needed to carry out their role in caring for someone with Alzheimer's disease and related dementias and to effectively manage increasing stress over time. Earlier evaluations of the Savvy Caregiver program demonstrated improvements on many key caregiving measures, including depression, caregiver burden, reaction to care recipient's problems, competence, mastery, and beliefs about caregiving.[1,2,3] In addition to increasing caregiver skills and confidence, previous evaluations found auxiliary benefits, such as an establishment of support networks for caregivers and an increased awareness of supportive services, such as respite.[4]

The grant program was implemented in accordance with the original evidence-based guidelines and consisted of 12 hours of education and training, given in 2-hour sessions, once a week, over a 6-week period. The program included a trainer's manual and a caregiver's manual. The goal was to deliver the Savvy Caregiver program to the state's diverse population of English-speaking caregivers and to demonstrate effects similar to those found in earlier research. A total of 120 classes were held during the grant period with 1,210 caregivers, of whom 978 completed the program; completers were defined as those attending four or more classes. The demand for the program exceeded capacity in the last year of the project, resulting in a waiting list of interested caregivers; additional courses were scheduled when possible.

The California Department on Aging collaborated with five Alzheimer's Association chapters in California to deliver the intervention. Each chapter developed its own informal local partnerships to facilitate the delivery of the program, including organizations trusted by specific ethnic groups, including hospitals and faith communities. The Partners in Care Foundation developed the project evaluation protocol, collected and analyzed data, and provided evaluation reports.

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Savvy Caregiver Program courses were promoted through printed materials that included flyers, websites, and newsletters. Electronic flyers were e-mailed to interested caregivers and posted on local Alzheimer's Association chapter websites, and information about courses was included on the California Department on Aging's website calendar of evidence-based programs. Recruitment focused heavily on caregivers who were receiving related services. For example, current clients and caregivers attending Alzheimer's Association programs and services were recruited to participate in the program. Partnering with an adult day care center, the program was able to recruit caregivers who would drop off their relative at the center and then attend Savvy Caregiver Program courses in the same location.

Several factors affected the project's ability to recruit ethnically diverse caregivers. For example, in many ethnically diverse communities, family caregivers self-identify as a son, daughter, spouse, or other family member and do not self-identify as a caregiver. Also, cultural norms in some ethnic communities discourage seeking help outside of the family. Seeking assistance and education from outside of the immediate family can be considered shameful.

To enroll more ethnically diverse caregivers, strategies included the following:

- Cosponsoring Savvy Caregiver program classes with an agency that was already trusted by a specific ethnic population. For example, in Los Angeles, the Alzheimer's Association chapter worked with Keiro Senior Healthcare, a large nonprofit organization serving the Japanese American community.

- Using Alzheimer's Association staff who were already involved with outreach to specific ethnic communities. Frequently, multicultural staff members went beyond the traditional aging network to include outreach to parent resource centers at elementary schools and health clinics and participated in ethnic festivals.

- Allowing additional time (4 weeks) for program promotion and one-on-one conversations with caregivers prior to enrollment to build a relationship and a sense of trust between the trainer and the caregiver.

- Offering Savvy Caregiver program classes in the evening to accommodate caregivers working full-time.

Once caregivers completed the course, they often promoted the courses by word of mouth. Frequently, Savvy Caregiver Program participants would tell other family members to attend the class and inform their friends, neighbors, members of their church congregation, and others of the program's value.

By the end of the grant period, about one-third of the caregivers served identified themselves as ethnically diverse. Sociodemographic characteristics of the participants are summarized in ***Table B-2***.

Table B-2
Sociodemographic Data on Participants in California's Evidence-Based Intervention Grant to Better Serve People with Alzheimer's Disease

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Age						
Under 60	15	2	351	40	366	21
60+	858	98	531	60	1,389	79
Age Missing	337	—	328	—	665	—
Gender						
Female	480	56	723	81	1,203	69
Male	378	44	167	19	545	31
Gender Missing	352	—	320	—	672	—
Geographic Location						
Urban	340	87	340	87	680	87
Rural	51	13	51	13	102	13
Geographic Location Missing	819	—	819	—	1,638	—
Relationship						
Spouse	375	42	375	42	750	42
Unmarried Partner	8	1	8	1	16	1
Child	442	49	442	49	884	49
Parent	2	0	2	0	4	0
Other Relative	49	5	50	6	99	6
Nonrelative	18	2	17	2	35	2
Relationship Missing	316	—	316	—	632	—
Ethnicity						
Hispanic or Latino	140	16	149	16	289	16
Not Hispanic or Latino	710	84	773	84	1,483	84
Ethnicity Missing	360	—	288	—	648	—
Race						
White—Non-Hispanic	566	71	628	66	1,194	69
White—Hispanic	68	9	120	13	188	11
American Indian or Alaska Native	2	0	4	0	6	0
Asian	59	7	71	8	130	7
Black or African American	87	11	91	10	178	10

(continued)

Table B-2 (continued)
Sociodemographic Data on Participants in California's Evidence-Based Intervention Grant to Better Serve People with Alzheimer's Disease

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Native Hawaiian or Other Pacific Islander	4	1	8	1	12	1
Persons Reporting Some Other Race	4	1	4	0	8	0
Persons Reporting Two or More Races	7	1	19	2	26	1
Race Missing	413	—	265	—	678	—
Veteran Status						
Veteran	126	32	51	13	177	22
Non-Veteran	268	68	349	87	617	78
Veteran Status Missing	816	—	810	—	1,626	—

— Not available or not applicable.

Outcomes of Intervention/Program

To assess the impact of the program on caregiver outcomes, participants were asked to fill out a questionnaire that contained measures of caregiver mastery, competence, depression, reaction to care recipient's memory and behavior problems, management of meaning, management of situation, and intent to institutionalize the person with dementia. Baseline data were collected prior to the first Savvy Caregiver Program session and follow-up assessments were conducted at 6 and 12 months post-intervention. Also, a satisfaction survey was completed by attendees at the end of each of the six sessions.

To analyze the impact of the program on the measures listed, except for the intent to institutionalize questions, the evaluators conducted regression analyses for each measure for all participants together and for the three ethnic groups separately. Overall, there were statistically significant improvements on the measures of competence, depression, reaction to care recipients' problems, management of meaning, and management of situation. In addition, caregivers were able to successfully sustain improvements from 6 months to 12 months post-enrollment.[5] Also, there was positive anecdotal feedback from participants; some caregivers reported that this was the first time they had spoken of their caregiving experiences and feelings, and some caregivers continued to contact each other after the course concluded.

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[5] There appeared to be a statistically significant decrease in *mastery* between baseline and 6 months and then an improvement, albeit not statistically significant, between 6 months and 12 months, when the analyses were conducted on all caregivers together. There were no statistically significant changes on the measure of mastery for the three ethnic groups. Mastery is a measure of how much control caregivers feel they have. A decline in caregivers' feeling of control might take place as their care recipients' conditions deteriorate.

Some of the caregivers used formal services for the first time through this project. Caregivers were given up to $500 each to address barriers to attendance at Savvy Caregiver Program classes; 137 caregivers used this funding for respite care, with in-home respite being the preferred type, followed by adult day services. A smaller number of caregivers used the money to offset transportation costs.

Infrastructure Development

Building on prior collaborative efforts, the California Department on Aging administered the project with the Alzheimer's Association California Southland Chapter. The California Southland Chapter subcontracted with Partners in Care for evaluation of the project and also subcontracted with the other four Alzheimer's Association chapters involved with intervention delivery for the project. Each chapter was responsible for collecting all required data; identifying internal staff to be trained to deliver the intervention; recruiting caregivers and distributing respite/transportation funds; and locating host sites for the program delivery, which included senior centers, adult day care centers, public libraries, churches, hospitals, and community organizations.

Dr. Kenneth Hepburn, who developed the Savvy Caregiver program, trained 24 Alzheimer's Association staff to deliver the intervention through a 2-day training session. Training included the philosophy of the model, data collection, and the importance of maintaining fidelity to the model. Additional coaching sessions were given to trainers who required help in developing group facilitation skills to ensure that (1) the intervention session material was presented in full, (2) all caregivers could participate in discussions, and (3) fidelity to the intervention was maintained. Because all trainers were already Alzheimer's Association staff, they had the required in-depth knowledge of Alzheimer's disease and related dementias.

The project encountered a challenge when evaluators delivering the 6- and 12-month post-intervention phone assessments encountered distraught caregivers. Because the evaluators lacked clinical skills and knowledge to assist these caregivers, a standard referral procedure was developed, as follows:

- For participants determined to be emotionally distraught, but not in any immediate danger, a care consultant at each chapter was identified to receive these referrals and follow up with participants within 24 hours.

- For participants determined to be suicidal or expressing suicidal ideation, suicide and crisis hotlines and mental health agencies were identified for immediate referral.

- Additionally, two evaluators attended a training provided by the Los Angeles County Department of Mental Health on the topic of elder suicide and prevention.

Each of the five Alzheimer's Association Chapters used fidelity monitoring tools to ensure that the program was implemented as intended and to monitor trainer quality. These tools included (1) consumer satisfaction surveys, (2) trainer feedback forms, (3) spot checking by a master trainer with experience delivering Savvy Caregiver programs, and (4) mentoring trainers who were less experienced or less comfortable with the intervention delivery. Trainer and mentor would meet prior to the session, review the curriculum, and debrief after the sessions.

Sustainability

The five Alzheimer's Association Chapters in California continue to offer the intervention through the Aging Services Network, using several strategies. However, there are no funds available to offer financial assistance to caregivers for respite or transportation needs related to class attendance. The Alzheimer's Association chapters are using several strategies for continuing the program:

- *Fee-for-service charging:* The Northern California Chapter charged caregivers a fee to attend the program. Scholarships are available for those who are unable to pay the fee. The fee does not pay for the total expense of the class; therefore, the chapter is using its general fund to cover the balance of the costs. The chapter does not believe that the fee has reduced participation in the program.

- *Private foundation grants:* The California Southland (Los Angeles) Chapter has successfully secured two 1-year grants for the continued delivery of the program. Under these grants, no fee is charged for caregivers to attend. Caregivers are requested to complete a depression measure at baseline and 6 months post-intervention. The data will be used to evaluate the effect of the program on depression.

- *Older Americans Act Title IIIE Funds:* Three chapters are using OAA Title IIIE funds to deliver the program, which can be billed as caregiver training.

- *Using volunteer trainers:* The California Southland Chapter has entered into discussion with Dr. Hepburn to develop a certification process to train individuals outside of the Alzheimer's Association staff. Currently, 10 individuals are being mentored by Savvy Caregiver Program trainers to develop their skills to deliver the program. This training method and the use of volunteers will be closely monitored and evaluated to determine whether it is an effective means to sustain the delivery of the program.

- *Assisted living facility underwriting of costs:* The Orange County Chapter received some financial assistance from assisted living facilities to host Savvy Caregiver Program training for family caregivers at their facilities. Frequently, the facilities furnish refreshments and offer a supervised area for the person with dementia to stay during the class time.

Lessons Learned and Recommendations for Future Efforts

Grant staff learned that no single recruitment strategy is effective for all caregivers, and self-identification as a caregiver is an important barrier. For middle-aged and younger caregivers, electronic correspondence appeared to be more successful in recruiting participants than traditional mail and paper flyers. This strategy eliminated the expense of mailing and increased the number of individuals receiving information about the program; for example, the flyers could easily be distributed electronically to large networks of professionals to disseminate.

Other issues were encountered during the training. For example, the term “savvy” was an unfamiliar word to most caregivers attending the course, even those whose primary language is English. Many had preconceived and negative ideas about the word, which seemed to imply something unsavory. Also, trainers reported that caregivers with fewer years of formal education or those who were educated in another country were not as comfortable with the training and the formal classroom setting. These caregivers reported feeling overwhelmed with and intimidated by the PowerPoint presentation, lecture portions of the sessions, homework assignments, and the caregiver manual. Moreover, some ethnic caregivers expressed the preference to be with other caregivers from the same ethnic background or similar cultural context. More informal methods of instruction were required.

Overall, the project’s measureable outcomes for ethnically diverse caregivers were similar to those in the original research study. However, the impact of the project went beyond the Savvy Caregiver Program curriculum by connecting caregivers to existing resources. Caregivers learned of other services, such as support groups and the Meals on Wheels program, and many used services for the first time.

The remaining challenges include bringing the program to scale to reach more caregivers, including ethnically diverse caregivers, those with lower levels of formal education, and those who reside in more rural areas of the state. As California prepares for the number of individuals living with Alzheimer’s disease and related dementias to sharply increase within the Asian/Pacific Islander and the Latino communities, the Savvy Caregiver Program will be one means to strengthen the informal network of family and friends who assume caregiving responsibilities.

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Innovative Practice Grant:
Georgia's Improving Term Care Options for Persons with Alzheimer's Disease and Their Caregivers

Introduction

The Tailored Caregiver Assessment and Referral® (TCARE®) protocol is an evidence-based, manualized protocol developed at the University of Wisconsin–Milwaukee, which guides care managers through an assessment and care planning process that helps to identify the sources and types of caregiver stress.[1] The protocol is grounded in the caregiver identity theory articulated by Rhonda J.V. Montgomery and Karl Kosloski.[2] Because the protocol is designed to assist with targeting appropriate services and creating highly individualized care plans, the services recommended for caregivers will be more appropriately tailored to their needs and strengths and caregivers served will be more likely to use these services. Consequently, the TCARE® protocol is expected to result in positive outcomes for caregivers and more effective use of resources.

Care managers or family specialists who want to use TCARE® must be trained and certified to (1) assess caregivers' needs, using the *Assessment* form; (2) interpret the scores on key measures to determine the types and level of need, using the *Assessment Summary Sheet*; (3) identify appropriate goals and support strategies, using the *Decision Maps*, and develop a list of service options that are locally available and consistent with identified goals and support strategies, using the *Guide for Selecting Support Services*; (4) consult with the caregiver to create a care plan that is appropriate and acceptable to the caregiver, using the *Care Plan Consultation Worksheet*; and (5) create the mutually agreed-upon care plan, using the *Caregiver Care Plan*.

The goals of the Georgia grant project were to evaluate the impact of TCARE® on caregivers and care managers in a community setting and to develop infrastructure to support its implementation statewide. The Georgia Division of Aging Services collaborated with three Area Agencies on Aging (AAAs), the Alzheimer's Association Georgia Chapter, and the Office of Applied Gerontology at the University of Wisconsin–Milwaukee (UWM) to implement the intervention.

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[1] Kwak, J., Montgomery, R. J. V., Kosloski, K., & Lang, J. (2011). The impact of TCARE® on service recommendation, use, and caregiver well-being." *Gerontologist, 51*(5), 704–713; Montgomery, R. J. V., Kwak, J., Kosloski, K., & Valuch, K. O'C. (2011). Effects of the TCARE® intervention on caregiver burden and depressive symptoms: Preliminary findings from a randomized controlled study. *Journal of Gerontology, Series B: Psychological Services and Social Sciences, 66*(5), 640–647; and Montgomery, R., & Kwak, J. (2008). TCARE: Tailored caregiver assessment and referral. *American Journal of Nursing, 108*(9 Supplement): 54–57.

[2] Montgomery, R. J. V., Rowe, J. M., & Kosloski, K. (2007). Family caregiving. In J. A. Blackburn & C. N. Dulmus (Eds.), *Handbook of gerontology: Evidence-based approaches to theory, practice, and policy* (pp. 426–454): John Wiley & Sons.

Outcomes of Intervention Program

A longitudinal randomized trial was conducted to assess the impact of TCARE® on caregiver identity discrepancy,[3] stress burden, depression, uplifts,[4] service use, and the caregiver's intention to place the care receiver in an alternate care setting. A uniform screening process was used to identify caregivers eligible for participation. Caregivers scoring medium or high on one or more measures of caregiver stress or depression were invited to take part in the demonstration and randomly assigned to the TCARE® or control group. Study participants included 12 care managers employed by the three participating AAAs. Of the 100 caregivers served by the agencies, 53 received the TCARE® protocol while 44 served as a control group and received standard services. Sociodemographic characteristics of the participants are summarized in ***Table B-3***.

Table B-3
Georgia Caregiver Assessment and Nursing Home Diversion: Improving Long-term Care Options for Persons With Alzheimer's Disease and Their Caregivers

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Total	__	100	—	100	—	100
Age						
Under 60	__	1	—	38	—	20
60+	—	99	—	62	—	80
Age Missing	—	—	—	—	—	—
Gender						
Female	—	53	—	83	—	68
Male	—	47	—	17	—	32
Gender Missing	—	—	—	—	—	—
Relationship						
Spouse	—	—	—	37	—	37
Unmarried Partner	—	—	—	0	—	0
Child	—	—	—	54	—	54
Parent	—	—	—	0	—	0
Other Relative	—	—	—	6	—	6
Nonrelative	—	—	—	3	—	3
Relationship Missing	—	—	—	—	—	—

(continued)

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[3] Identity Discrepancy is defined as a psychological state that accrues when there is a disparity between the care activities in which a caregiver is engaging and his or her identity standard. An example, which demonstrates that it is not the task but how you feel about the task that is causing the discrepancy, would be a son providing personal care for his mother.

[4] Uplift is defined as a positive psychological outcome associated with caregiving.

Table B-3 (continued)
Georgia Caregiver Assessment and Nursing Home Diversion: Improving Long-term Care Options for Persons With Alzheimer's Disease and Their Caregivers

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Ethnicity						
Hispanic or Latino	—	0	—	0	—	0
Not Hispanic or Latino	—	100	—	100	—	100
Ethnicity Missing	—	—	—	—	—	—
Race						
White—Non-Hispanic	—	53	—	53	—	53
White—Hispanic	—	0	—	0	—	0
American Indian or Alaska Native	—	1	—	0	—	.5
Asian	—	0	—	0	—	0
Black or African American	—	44	—	44	—	44
Native Hawaiian or Other Pacific Islander	—	0	—	1	—	.5
Persons Reporting Some Other Race	—	0	—	0	—	0
Persons Reporting Two or More Races	—	2	—	2	—	2
Race Missing	—	—	—	—	—	—

— Not available or not applicable.

Note: Grants funded during this time period were not required to report on Age Missing, Urban and Rural categories of Geographic Location, Veteran Status, or the Person with Dementia's Relationship to the Caregiver. Final data submitted by GA 90AI0006 contains discrepancies in the following categories: PWD data contain discrepancies within every demographic category; Caregiver Gender and Ethnicity data also contain discrepancies.

Data for each caregiver were collected at the time of enrollment and at 3-month intervals for up to a 1-year period. Descriptive analyses were conducted to provide profiles of characteristics of caregivers and care managers, while the effects of the TCARE® protocol were tested by using random effects regression growth curve analysis and random intercept regression analysis.

The six care managers assigned to the TCARE® group participated in intensive training on the protocol, while the six care managers in the control group continued to use normal or customary practices. A process evaluation was conducted to document and maintain the fidelity of implementation of the TCARE® process by the care managers. The process evaluation found that the TCARE® training process adequately prepared care managers to consistently and accurately implement the TCARE® protocol and maintain fidelity with the protocol over time.

Results from the evaluation found statistically significant differences between the TCARE® and control groups in three areas: TCARE® caregivers reported significantly lower levels of identity discrepancy, stress burden, and depression. Over 9 months, caregivers receiving the TCARE® intervention continued to improve in these areas, while caregivers in the control group declined. Although not statistically significant, caregivers in the TCARE® group also experienced a decrease in their desire to place the care receivers in an institutional setting, and an increase in uplifts over time, while caregivers in the control group experienced the opposite.

Only seven types of services were used by more than five caregivers across the groups regardless of recommendation by care managers. In order of frequency of use, these types of services included in-home services, medical/behavioral health services, counseling or social psychological education, support groups, caregiver education focused on skills or information, adult day services, and assistive technologies. With the exception of in-home services, a larger portion of the caregivers in the TCARE® group reported using each of these services.

There were significant differences between the groups' care plans with regard to the inclusion of support services that address the emotional strains, stress, and depression associated with caregiving. Care plans for caregivers in the TCARE® group included a wider range of service types and were more apt to include services that would address the psychosocial and physical needs of the caregiver. Two of the service categories, medical/behavioral health services and support groups, were included *only* in care plans for caregivers in the TCARE® group. No one in the control group used medical or behavioral health services and only three individuals attended a support group.

The differences observed in types of services recommended is consistent with the fact that the TCARE® Assessment Tool includes a screen for depression and health issues and prompts care managers to make recommendations to caregivers to seek behavioral or medical health services when caregivers' scores indicate high levels of depression or poor health. Similarly, the number of recommendations for attendance of support groups reflects the decision algorithms that are built into the TCARE® protocol, which identify support groups and educational topics that could potentially benefit caregivers experiencing high levels of stress or depression.

The evaluation also assessed care managers' job satisfaction and burnout. The small sample size did not allow for sophisticated analyses of the data, but the descriptive findings indicate higher levels of overall job satisfaction, more satisfaction with job demands, lower levels of burnout, and higher levels of satisfaction with administrative challenges for care managers using the TCARE® protocol. These findings echo the general positive view of the protocol expressed anecdotally by care managers.

Infrastructure Development

A goal of the demonstration project was to develop an infrastructure to support and expand implementation of the TCARE® protocol throughout the state. Activities directed toward this goal included augmenting, testing, and refining an electronic version of the TCARE® process. The TCARE®*e* web-based system allows care managers to enter assessment data into a website and uses those data to create a care consultation worksheet and care plan, and to fill out various administrative forms. It is estimated that this computerization will halve the time that care managers spend on the paper-and-pencil version.

In collaboration with the Georgia Division of Aging Services and the Atlanta Regional Commission AAA, the TCARE® team at UWM created a prototype linking Georgia's Enhanced Services Program resource database to the TCARE®*e* web-based system, making it easier for care managers to link caregivers to locally available services. Twenty-four care managers and administrators were trained on the TCARE®*e* system and feedback from a user survey provided guidance for making changes and improvements to the system.

The TCARE® team at UWM also trained and certified seven master trainers to train other care managers throughout the state; the seven trainees included three care managers, two supervisors, and two intake staff who had previously been certified to use TCARE®. The training protocol for TCARE® master trainers included an initial 2-day intensive session and a mentored apprentice training. Fifty additional care managers have now been trained and certified through a web-based or in-person TCARE® training. These efforts have laid the foundation for replicating the protocol throughout the state.

Sustainability

As a result of the grant project, the Georgia Department of Aging Services is requiring the use of the TCARE® protocol in all 12 of the state's AAAs. This decision was influenced by federal support for implementing evidence-based programs, interest at the state level in diverting individuals from nursing homes, and the focus on evidence-based caregiver support in the next 4-year state aging plan.

As of the final report, the state was involved in activities that will assist with the statewide implementation, including (1) revising state policies on client assessment, care management, and in-home respite to be in alignment with TCARE®; and (2) disseminating information about the TCARE® model to the 12 AAAs to be used as they develop their 4-year area plans. The Department has also entered a contractual agreement with UWM to receive training and certification, and to use the TCARE® protocols.

Lessons Learned and Recommendations for Future Efforts

To assist with TCARE® implementation, Georgia recommends the following strategies:

- Educate AAAs on the benefits of TCARE® caregiver assessment before introducing them to protocols, and establish a TCARE® Work Team with representation from each AAA, so that there will be a point person for disseminating information to other staff.

- Provide regular written communication to the AAA network regarding implementation development and plans and allow AAAs to phase in TCARE® gradually. For example, an AAA could begin by using it with existing programs where the caregiver is the client. Then, in a subsequent year, TCARE® can be added at the Aging and Disability Resource Center (ADRC) level (using screens) after care managers are already proficient in TCARE®.

- Develop a team of TCARE® master trainers from the different geographic regions where care managers reside. Teams of three master trainers are recommended, because each trainer will have less material to prepare. This is especially important because master trainers, in most instances, already have full-time jobs.

- Define the term “care manager” (i.e., those persons who arrange for services for those being served). Communicate clearly to AAA administrators that the 2.5-day training and subsequent care manager webinars leading to certification are for care managers using the TCARE® full assessment and protocols and the TCARE® screen. Let them know there will be a separate webinar training for ADRC/intake staff on use of the TCARE® screen.

- Limit the number of care manger trainees to 16 per class to ensure that master trainers will be able to provide one-on-one attention and that work groups are small enough for everyone to be able to participate.

Recommendations for integrating TCARE® with Nursing Home Diversion (NHD) and other community living programs include providing a webinar regarding the use of the state’s NHD targeting criteria for those persons conducting TCARE® screens on caregivers (a brief PowerPoint format works well). In most instances, ADRC/intake staff will conduct the screenings for both types of program.

Innovative Practice Grant:
A Dementia Crisis Support Program: The Kansas Bridge Project

Introduction

The goal of the Dementia Crisis Bridge Project (Bridge) was to increase dementia competency throughout the Aging Network and mental health centers in Kansas to provide crisis support to individuals and families facing the neuropsychiatric complications (e.g., depression, anxiety, agitation, psychosis) of Alzheimer's disease or related dementia (ADRD).[1] The Kansas Department on Aging collaborated with four Area Agencies on Aging (AAAs) to implement the project, and the University of Kansas served as project evaluator. The Alzheimer's Association, Heart of America Chapter, provided two Dementia Crisis Support Coordinators (Bridge Coordinators) and played a key role in developing an educational curriculum.

Each Bridge Coordinator served a mainly urban AAA and one rural AAA, covering 18 counties in total. The primary responsibility of the Bridge Coordinators was to assume the role of point person for crisis calls associated with ADRD. The Bridge Coordinators provided services that included (1) assessing factors contributing to the neuropsychiatric challenges, (2) providing disease information, (3) advocating for appropriate treatment, and (4) bridging communication needs with physicians and other involved professionals. They also provided resources and counseling to family members on grief issues, communication, recognizing pleasurable experiences, and management of their own needs.

The grant partners also created resources to advance cross-training of aging and mental health professionals, including a guidebook exploring possible responses to neuropsychiatric symptoms and a toolkit that combined assessment tools and intervention guidance from other states and national sources. These materials were distributed to individuals and in training programs provided to, among others, the AAAs and Mental Health Centers.

Outcomes of Intervention Program

The target population included families experiencing significant neuropsychiatric challenges. Clients were referred to the program primarily by AAA staff, but referrals were also received from mental health center staff, geriatric psychiatric inpatient unit social service staff, Adult Protective Services, and long-term services and supports staff. Of 178 referrals, 69 did not involve neuropsychiatric crisis and were referred to other existing dementia services; another 16 declined participation in the intervention. Ultimately, 93 families enrolled in the project: 46 from urban counties, 46 from rural counties, and 1 from a frontier county. Sociodemographic characteristics of the participants are summarized in ***Table B-4***.

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[1] "Eighty percent of individuals with a dementia will experience neuropsychiatric (behavioral and affective) symptoms. The many serious consequences of these complications are greater impairment in activities of daily living, more rapid cognitive decline, worse quality of life, earlier institutionalization and greater caregiver depression." Lyketos, C., Lopez, O., Jones, B., Fitzpatrick, A., Breitner, J., & DeKosky, S. (2002). Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment. *Journal of the American Medical Association*, *288*(12).

Table B-4
Sociodemographic Data on Participants in the Kansas Bridge Project

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Total	93	100	108	100	201	100
Age	3	3	54	50	57	28
Under 60						
60+	90	97	54	50	144	72
Age Missing	—	—	—	—	—	—
Gender	55	59	81	75	136	68
Female						
Male	38	41	27	25	65	32
Gender Missing	0	—	0	—	0	—
Relationship	—	—	42	39	42	39
Spouse						
Unmarried Partner	—	—	0	0	0	0
Child	—	—	54	50	54	50
Parent	—	—	1	1	1	1
Other Relative	—	—	6	6	6	6
Nonrelative	—	—	4	4	4	4
Relationship Missing	—	—	1	—	1	—
Ethnicity	3	3	5	5	8	4
Hispanic or Latino						
Not Hispanic or Latino	90	97	99	95	189	96
Ethnicity Missing	0	—	4	—	4	—
Race	66	72	80	75	146	73
White—Non-Hispanic						
White—Hispanic	3	3	4	4	7	4
American Indian or Alaska Native	1	1	1	1	2	1
Asian	1	1	3	3	4	2
Black or African American	20	22	18	17	38	19
Native Hawaiian or Other Pacific Islander	0	0	0	0	0	0
Persons Reporting Some Other Race	0	0	0	0	0	0
Persons Reporting Two or More Races	1	1	1	1	2	1
Race Missing	1	—	1	—	2	—

— Not available or not applicable.

Note: Grants funded during this time period were not required to report on Age Missing, Urban and Rural categories of Geographic Location, Veteran Status, or the Person with Dementia's Relationship to the Caregiver. Final data submitted by KS 90AI0026 contain discrepancies in the following categories: Caregiver Relationship, Ethnicity, and Race data.

The Bridge Coordinators served as consultants for 79 additional families who were not officially enrolled in Bridge, providing assessment and intervention choices and recommendations through an already involved community professional. By the end of the project, 201 initial assessment visits were conducted and 736 follow-up phone calls were made to families and collateral contacts, such as physicians.

The evaluation found that a significant number of individuals with dementia experiencing neuropsychiatric crisis had either a preexisting mental health diagnosis or indicator of previous mental health challenges. Moreover, some caregivers of persons with neuropsychiatric symptoms also had preexisting mental health issues.

Seventy-eight of the 93 participating families completed pre- and post-intervention assessments. The outcomes included (1) reduction of neuropsychiatric symptoms, (2) reduction of caregiver distress related to the neuropsychiatric symptoms, (3) reduction in number of psychiatric rehospitalizations, (4) improved caregiver confidence in recognizing and addressing warning signs of possible psychiatric complications, and (5) project partners' perception of improved service to clients with ADRD.

The Geriatric Depression Scale and the Neuropsychiatric Inventory Questionnaire, which measures both the severity of neuropsychiatric symptoms and caregiver distress associated with them, was given at initial assessment and at the end of the intervention. Findings included improved caregiver reaction to the care receiver's neuropsychiatric symptoms; decreased caregiver distress; and significant reduction in care receivers' symptoms of anxiety, problems sleeping, and hallucinations. Caregivers also reported a significant increase in confidence in their ability to manage difficult dementia behaviors.

Information was collected on the number of hospitalizations that had occurred in the previous year and the frequency of rehospitalizations. This information was compared to a control group derived from individuals outside of the targeted area who had been discharged from geriatric psychiatric hospitals.[2] In the Bridge project, hospitalization rates reported in the pre- and post-tests remained essentially the same. Closer examination revealed that rehospitalizations in the intervention group were essentially absent. The static hospitalization rates reflected advocacy for initial geriatric psychiatric hospitalization for those individuals who manifested neuropsychiatric symptoms severe enough for hospitalization yet had not been extended that option prior to the project. This was primarily related to insufficient communication between the family and the physician or prior absence of connection to physicians/medical care.

Additional findings included the avoidance of long-term care facility discharges because of neuropsychiatric symptoms and the possible delay in nursing home placement. Although less is documented about long-term care facility discharges, it is known that discharges occur

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[2] Comparing rehospitalization rate to the control group presented some difficulty. Significant challenges occurred in securing a sufficient sample of control group participants, which impacted comparative ability in this area. Woo and colleagues, in their 2006 study of 424 geriatric psychiatric admissions, found that 81% of readmissions occurred in the first 3 months after discharge. Woo, B., Golsham, S., Allen, E., Daly, J., Dilip, J., & Sewell, D. (2006). Factors associated with frequent admissions to an acute geriatric psychiatric inpatient unit. *The Journal of Geriatric Psychiatry and Neurology*, *19*(4), 226–230.

regularly. Data were collected on the number of discharges prior to project involvement and post-intervention. Fourteen of the 93 persons involved imminent risk of long-term care facility discharge because of the neuropsychiatric challenges. For 10 of those 14 persons, the eviction was avoided because of Bridge interventions. Similarly, for 45 of the 93 persons, the neuropsychiatric challenges placed the community dwelling person at risk of nursing home placement. For 24 of those 45 persons, placement was believed to be delayed because of the Bridge interventions.

Finally, project partner interviews were conducted to assess the value of having Dementia Crisis Support Coordinators in state aging offices. All four of the partnering AAAs reported that the Bridge project had enhanced their services for individuals with dementia and agreed that it was important for the Dementia Crisis Support Coordinator to be part of their offices.

Infrastructure Development

During the grant period, 100 outreach visits to inform the professional community about the Bridge program and neuropsychiatric challenges were made to Adult Protective Services, geriatric psychiatric acute hospital settings, home health agencies, hospitals, nursing homes, mental health centers, physician offices, senior centers, and the Long-Term Care Ombudsman Program. Also, toolkits that included neuropsychiatric symptom screening tools, support materials for professionals (educational materials on dementia and associated neuropsychiatric symptoms), and educational handouts for families were distributed to 21 physician offices.

The four partnering AAAs integrated the Bridge Coordinators with their staff, providing physical space for them and creating systems to improve the response to clients facing neuropsychiatric challenges. The Bridge Coordinators each possessed a Master’s in Social Work and were supervised from the Alzheimer’s Association, Heart of America Chapter, by a Licensed Clinical Social Worker with geriatric psychiatric experience. They attended an orientation prior to client contact, which included an overview of the partner agencies; content-specific education regarding ADRD, mental health, and aging issues; procedural information for the project; and safety issues.

Resources were developed to advance cross-training of aging and mental health professionals, including “The Neuropsychiatric Symptoms of Dementia: A Visual Guide to Response Considerations” that served as a key training tool. The guide describes common neuropsychiatric symptoms and possible responses to address specific challenges associated with the symptoms in an easy-to-use format that allows professionals to identify problems and possible solutions at a glance. Toolkits were also developed that included the Neuropsychiatric Inventory Questionnaire, which was used as one of the evaluation tools for this project. These materials were distributed both individually and in training programs; 821 copies of the Neuropsychiatric Visual Guides were disseminated.

Trainings were held with individual AAAs, the statewide conference for AAA Information and Referral staff, Adult Protective Services, the Kansas Long-Term Care Ombudsman program, case managers of a large insurance company providing mental health carve-out coverage, the statewide annual meeting for Long-Term Care Surveyors, and six Mental Health Centers that serve a combined 30 counties. This was the first time an Alzheimer’s

Association Chapter provided training to mental health staff. Prior to the training, mental health staff said they did not see individuals with neuropsychiatric symptoms related to dementia. However, after training, mental health staff agreed that they had seen clients like this but did not recognize them.

Sustainability

The Kansas Department on Aging has designated funds—through a state workforce enhancement grant—to provide training to long-term care facilities. Additional funds have also been secured through a private foundation to assist with travel costs associated with ongoing Bridge services, and one of the partnering AAAs has committed to ongoing support of Bridge services through a counseling contract. The Alzheimer's Association, Heart of America Chapter, also recognized the value of the project and will continue the services with current staff.

Lessons Learned and Recommendations for Future Efforts

Despite the fact that there are many services that can assist with neuropsychiatric challenges associated with ADRD, many caregivers are told that behavior and mood issues are just part of the disease. Often caregivers do not realize that some of these neuropsychiatric symptoms can be treated, and this can lead to underuse of respite and other support services, and the imbalance of inpatient versus outpatient services. Education of frontline workers can potentially change this imbalance. Bridge Coordinators filled an unmet need in the community. Care coordination is important in managing neuropsychiatric symptoms in persons with ADRD and intervention when a person is experiencing neuropsychiatric symptoms that may delay nursing home placement. The Bridge project holds the potential for delaying nursing home placement and making care in the home setting possible for a longer period of time.

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Innovative Practice Grant:
Minnesota ADSSP Innovation Early Stage Grant

Introduction

The Minnesota Early Memory Care Initiative (EMCI) intervention built on the Memory Care Framework refined in Minnesota's earlier Alzheimer's Disease Demonstration Grants project, *Working Together*. The objective of the EMCI project was to increase the state's effectiveness by adapting the Memory Care framework to focus on people with early-stage dementia. Unlike most Alzheimer's initiatives, the EMCI addresses the person with memory loss, not just the care partner. The goal was to give early-stage clients optimal control over their lives by helping sustain cognitive function, reducing premature decline, and moderating the negative impacts on care partners.

Early-stage dementia care practice guidelines were developed, based on the experience of previous demonstrations, national best practices identified by the Alzheimer's Association, and guidance from physician champions. The purpose was to embed the new practices into the ongoing services, clinics, agencies, and governmental organizations to ensure that best early-stage dementia practices are maintained. Four EMCI project sites were developed in cooperation with four Area Agencies on Aging (AAAs) and the Minnesota-North Dakota Alzheimer's Association Regional Office to implement the Early Memory Care Practice Guidelines. Each of the AAAs selected a local organization to be a Memory Care site. The sites also pursued collaborative relationships with local clinics that indicated an interest in participation. At each EMCI site people with early symptoms of dementia were identified and:

- Received a referral for a complete medical workup at their clinic
- Received individual TCARE® assessments designed for persons with early memory loss and for their care partners
- Engaged in self-care planning, sharing the results with their care partners and their clinic
- Received ongoing coaching, education, and resources tailored to early-stage dementia, including exercise, nutrition, financial counseling referrals, driving guidance and other issues

The EMCI site memory care consultants and medical clinic partners, in cooperation with the Alzheimer's Association, implemented an early-stage education campaign that included presentations to local groups, a media campaign, outreach to key organizations, and early-stage dementia materials developed by the Alzheimer's Association. In addition, the question "Do you have memory concerns?" was added to the MinnesotaHelp.Info™ assessment protocol to be routinely asked of all consumers entering through the single entry point via the phone, in person, or the web.

Outcomes of Intervention Program

The project goal was to screen 1,000 persons for early-stage dementia and recruit 100 individuals for the EMCI program who would be supported through the coordinated implementation of the Early Memory Care Practice Guidelines in medical and social service organizations. A total of 1,281 screenings were conducted and 103 people subsequently enrolled in the EMCI program, of whom 62 were Hispanic (43 people with early memory loss and 19 care partners); the remainder were non-Hispanic Caucasians. Sociodemographic characteristics of the participants are summarized in ***Table B-5***.

Quality of life outcomes were measured prior to service and at the end of the project using validated instruments, which were embedded in the assessment. The assessment results were entered into a database provided by the evaluator who completed the data analysis and reported the results.[1] Univariate statistics (frequency distributions, calculation of mean, median, and mode statistics) were analyzed for summary scales and other items. T-tests were also used to examine significant change over time in key outcome measures, and correlations were conducted to determine whether any background variables were associated with change in outcomes over time.

The pre-post evaluation of 61 persons with dementia and 12 care partners who completed the final assessment showed the following results:

- Improved quality of life and coping skills of the person with dementia—including an increase in the median score for activity and memory effectiveness—and reduced depression.
- Slightly increased depression but reduced burden and stress in the care partner, including a reduction in the median score on objective stress, subjective stress, and relational deprivation.

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[1] Quality of life was measured using the Quality of Life-Alzheimer's Disease instrument [Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging, 5*(1), 21–32], which measures the person with dementia's mood, physical condition, interpersonal relationships, ability to participate in meaningful activities, and financial situation to create an overall assessment of global well-being. Overall, care partners scored the person with dementia's quality of life higher than they did themselves. Care partners' perception was the quality of life of the person with dementia and their feelings of depression were better than the person with dementia him- or herself expressed.

Table B-5
Sociodemographic Data on Participants in the Minnesota Early Memory Care Initiative

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Total	64	100	39	100	103	100
Age						
Under 60	4	6	22	59	26	26
60+	60	94	15	41	75	74
Age Missing	—	—	—	—	—	—
Gender						
Female	45	70	32	82	77	75
Male	19	30	7	18	26	25
Gender Missing	0	—	0	—	0	—
Relationship						
Spouse	—	—	9	24	9	24
Unmarried Partner	—	—	0	0	0	0
Child	—	—	28	76	28	76
Parent	—	—	0	0	0	0
Other Relative	—	—	0	0	0	0
Nonrelative	—	—	0	0	0	0
Relationship Missing	—	—	0	—	0	—
Ethnicity						
Hispanic or Latino	43	67	19	49	62	60
Not Hispanic or Latino	21	33	20	51	41	40
Ethnicity Missing	0	—	0	—	0	—
Race						
White—Non-Hispanic	21	33	20	51	41	40
White—Hispanic	28	44	19	49	47	46
American Indian or Alaska Native	0	0	0	0	0	0
Asian	0	0	0	0	0	0
Black or African American	0	0	0	0	0	0
Native Hawaiian or Other Pacific Islander	0	0	0	0	0	0
Persons Reporting Some Other Race	0	0	0	0	0	0
Persons Reporting Two or More Races	15	23	0	0	15	15
Race Missing	0	—	0	—	0	—

— Not available or not applicable

Note: Grants funded during this time period were not required to report on Age Missing, Urban and Rural categories of Geographic Location, Veteran Status, or the Person with Dementia’s Relationship to the Caregiver. Final data submitted by MN 90AI0008 contain discrepancies in the following categories: Caregiver Gender and Under 60 data.

Infrastructure Development

Following the convening of an expert clinic advisory board and extensive review by EMCI site staff, the Early Memory Care Practice Guidelines were created and served as the practice “blueprint” for the EMCI program. All four Memory Care sites implemented the guidelines. Adoption occurred through a variety of trainings for staff and clinics collaborating on the EMCI, including an informational meeting with nurses and doctors at a local clinic, a Department of Human Services meeting, the annual Age Odyssey conference, and other trainings on state-developed screening tools, chronic disease management, and other programs.

Establishing and maintaining strong working relationships with the clinics was time-consuming, especially with sites in widely scattered rural communities across the state. Much work occurred in this area, and several EMCI sites secured physical space in clinics by the end of the project. Travel for training, also time consuming, was minimized through the use of technology. For example, video conferences were used to provide large-scale, early memory care training, and regular conference calls reinforced the collaborative learning and offered opportunities to identify needed additional training.

Other infrastructure development included collaborating with local hospital staff to create a referral form for people who showed signs of memory loss, which enabled staff to refer them to the Minnesota River AAA Memory Care site. Also, an Elder Service Provider Network (ESPN) consisting of eight agencies/programs serving the Leech Lake area was officially established. Monthly meetings were conducted with the Minnesota Chippewa Tribe AAA as one of the lead agencies to act as a referral and networking source. AAA staff felt that ESPN providers would serve as the AAA’s “eyes and ears” in the American Indian community on dementia problems.

Sustainability

What emerged from the EMCI was a portrait of two extremes: on one end, one site was able to employ a fully integrated memory care consultant who interacted with and managed communication with primary care providers and demonstrated the potential of early-stage dementia care (with a second site beginning to do so in the latter stages of the project). On the other end of the spectrum were sites that spent most of the project time attempting to establish channels of referral, build working relationships with partner clinics, and provide community and clinic education regarding the importance of early-stage dementia.

However, by project end, all participating medical/health clinics had embedded/implemented the guidelines to identify people in the early stages of the disease and their care partners were engaged in diagnosis of Alzheimer’s disease and provided a handoff to their partnering community agency for care planning and coaching services. In addition, hundreds of providers statewide were trained in early identification of dementia.

To ensure that the work begun by this initiative continues, the early memory care consultants were embedded within Older Americans Act Title III and National Family Caregiver Program–funded positions. Also, Minnesota is participating in the Centers for Medicare & Medicaid Services’ Multi-Payer Advanced Primary Care Practice demonstration project. The Alzheimer’s Association and the Minnesota Board on Aging are jointly exploring avenues to ensure that dementia capability is built into this demonstration.

Lessons Learned and Recommendations for Future Efforts

Denial that anything is wrong presents a continuing challenge in offering services to people with dementia and their caregivers. These challenges are greater for people with early-stage Alzheimer's disease because people feel that they are "not ready" for further assessment or do not want others to know that they have dementia. Memory care consultants often have to begin with an approach of simply providing information, in the hope that as situations and needs change, having resources in hand may eventually benefit individuals and families, and could result in later enrollment in the EMCI.

Also, the development and maintenance of a strong and trusting relationship with physicians took considerable time, but was critical to the implementation of the EMCI. Many physicians had no idea a program such as the EMCI existed and how it could benefit people with early-stage dementia.

Other innovations that would be valuable for the aging network include the following:

- The Live Well at Home Rapid Screen© is a Minnesota tool developed to identify the risk of nursing home admission or spend down to Medicaid. Completion of the brief Rapid Screen identifies risks in seven evidence-based risk categories, including memory loss. It addresses issues of memory loss within the context of other issues that might interfere with an individual's ability to continue living independently in the community.

- The SLUMS[2] test provides a simple approach to determining the acuity of an individual's memory loss and is required for all individuals who enroll in the EMCI (unless they have a medical diagnosis of early-stage dementia). EMCI partner clinics were very interested in the SLUMS test as a possible dementia screening and staging instrument.

- The Minnesota Chippewa Tribe Memory Quiz, based on the Alzheimer's Association's 10 Warning Signs and modified for the American Indian community, has been endorsed by the Alzheimer's Association Minnesota/North Dakota Chapter.

- The Alzheimer's Association developed a consumer/family early memory care folder and a physician toolkit that is given to families by their physicians. The folders are an important tool that physicians use to engage in the conversation with the person with dementia and their care partners.

- The early memory care wiki is a virtual interactive medium for memory care consultants, an online manual that serves as a communication device where consultants can find the most recent version of any of the tools and forms and the guidance on implementation of the intervention. Memory care consultants can also

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[2] Tariq, S. H., Tumosa, N., Chibnall, J. T., Perry, H. M. III, & Morley, J. E. (2006). The Saint Louis University Mental Status (SLUMS) examination for detecting mild cognitive impairment and dementia is more sensitive than the Mini-Mental Status Examination (MMSE)—A pilot study. *American Journal of Geriatric Psychiatry, 14*, 900–910.

receive mentoring and coaching. The wiki is password protected and is only available to memory care consultants.

Overall, the outcome evaluation provides promising evidence that the Early Memory Care Practice Guidelines could result in an effective, high-quality model for enhancing care coordination during the initial phases of Alzheimer's disease or similar dementias. However, more rigorous research with a larger sample is needed to test an intervention.

Evidence-Based Grant:
Minnesota's New York University Caregiver Intervention Translation:
Family Memory Care I

Introduction

The New York University Caregiver Intervention (NYUCI) program was developed by clinicians at the New York University-Alzheimer's Disease Center.[1] Formalized by Mary Mittelman, DrPH, and colleagues, the program consists of one initial caregiver counseling meeting, four family sessions, and a subsequent caregiver counseling meeting, as well as additional caregiver consultant time for screening, assessment/reassessment, ad hoc calls, e-mail or telephone communication, information and referral, caregiver support group participation, and other services to the caregiver and family.

The NYUCI translation in Minnesota is called Family Memory Care (FMC). It has been implemented through three distinct Administration on Aging (AoA) grants (90AZ2809/01, 90AE0323, and 90AE0336). Under the second and third grants, the state expanded the intervention to more regions of the state and more family caregivers. Four sites were established under the first grant, and another five sites were added under the second grant. In 2010, one of the sites from the first grant closed, and the state's FMC project continued with eight sites until additional sites were added under the third grant.

This case study discusses the implementation of the second grant (90AE0323), which ended in 2012. Some individuals who were enrolled in the first grant (90AZ2809/01) but continued in the intervention and received services provided under the second grant are included in the numbers of persons served in the Minnesota Final Report for the second grant (90AE0323) and in this case study. Individuals enrolled and served under the third grant (90AE0336) are not included in the numbers of persons served in the Minnesota Final Report for 90AE0323 or this case study.

The purpose of the intervention was to improve the ability of caregivers to withstand the difficulties of caregiving by improving social support and minimizing family conflict, and to embed FMC consultation within the already funded Older Americans Act (OAA) Title IIIE funded caregiver consultation network. The outcomes to be achieved were (1) reduced negative impact of caregiving behaviors and decreased level of depression, (2) enhanced support network composition and effectiveness for caregivers to delay or prevent institutionalization, and (3) fidelity to the original research and cost-effectiveness. The goal of the project was to recruit, assess, and provide the intervention for 200 caregivers.

The grant project was directed and coordinated by the Minnesota Board on Aging in partnership with five Area Agencies on Aging (AAAs). To participate in the FMC program, a person had to be the primary caregiver living with the person with dementia in the community, and had to be their spouse or partner. This requirement was modified in 2011, in situations where the person with dementia did not have a spouse or partner, to allow enrollment of adult child

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[1] Mittelman, M. S., Haley, W. E., Clay, O. J., & Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology, 67*, 1592–1599.

primary caregivers living with the person with dementia in the target community where it was found that often minority elders did not have spouses. One adult child caregiver was enrolled in the second grant program (90AE0323).

The program recruited 162 caregivers, which was somewhat lower than anticipated; 119 caregivers completed the intervention. There were several factors that created barriers to recruitment:

- It was challenging for the FMC consultants in the rural areas to recruit participants. FMC is an intensive family counseling intervention and caregivers in this age group in rural Minnesota tend not to participate in counseling-related services. They are also reluctant to involve their families, and the number of sessions seems burdensome to some.

- Many families do not have time to participate in the family sessions. To address this challenge, the state is working with AAAs to use usual caregiver consultation as a feeder system for FMC, identifying those that qualify and introducing them to the FMC service. In addition, the FMC consultants are more carefully screening caregivers who qualify to ensure that the commitment to fully engage is in place before the service begins. This has resulted in lower initial participation but higher completion rates.

Recruiting continuously among groups and individuals that knew the consultants well was the best overall strategy. In addition, to the degree to which FMC consultants were known and respected in their community, the greatest recruitment success factors included (a) FMC consultant comfort level with outreach; (b) the amount of time spent on outreach; and (c) direct engagement in outreach activities, including presentations, writing articles, and meeting with key contacts.

Outcomes of Intervention/Program

The implementation experience of all the Minnesota organizations that adopted and delivered FMC under the three AoA grants was followed and evaluated from the fall of 2007 through the summer of 2012 by Deborah Paone of Paone & Associates, LLC, an independent consulting practice. The evaluation used several approaches, including analysis of data collected at enrollment and reassessments; and a process evaluation based on site visits, narrative reports by FMC consultants, surveys, telephone interviews, and cost data collected by the sites.

Under the second grant (90AE0323), nine FMC consultants provided services for 162 caregivers, including 119 caregivers who were recruited and assessed under this grant, and 43 caregivers who had been recruited and assessed under the first grant (90AZ2809/01) but continued to receive FMC services under the second grant. Of the 162 caregivers who were assessed, 119 completed the intervention, including 85 of the caregivers recruited and assessed under the second grant and 34 additional caregivers who had been recruited and assessed in the first grant and completed the intervention under the second grant. Sociodemographic characteristics of the participants are summarized in ***Table B-6***.

Table B-6
Sociodemographic Characteristics of Participants in Minnesota's NYUCI Translation: Family Memory Care I

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Total	158	—	162	—	320	—
Age						
Under 60	9	6	14	9	23	7
60+	149	94	148	91	297	93
Age Missing	0	—	0	—	0	—
Gender						
Female	70	44	96	59	166	52
Male	88	56	66	41	154	48
Gender Missing	0	—	0	—	0	—
Geographic Location						
Urban	57	36	57	35	114	36
Rural	101	64	105	65	206	64
Geographic Location Missing	0	—	0	—	0	—
Relationship						
Spouse	154	98	158	98	312	98
Unmarried Partner	1	1	1	1	2	1
Child	0	0	1	1	1	0
Parent	1	1	0	0	1	0
Other Relative	0	0	0	0	0	0
Non-relative	1	1	1	1	2	1
Relationship Missing	1	—	1	—	2	—
Ethnicity						
Hispanic or Latino	1	1	2	1	3	1
Not Hispanic or Latino	128	99	158	99	286	99
Ethnicity Missing	29	—	2	—	31	—
Race						
White—Non-Hispanic	127	97	159	98	286	98
White—Hispanic	1	1	2	1	3	1
American Indian or Alaska Native	2	2	0	0	2	1
Asian	0	0	0	0	0	0

(continued)

Table B-6 (continued)
Sociodemographic Characteristics of Participants in Minnesota's NYUCI Translation: Family Memory Care I

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Black or African American	0	0	0	0	0	0
Native Hawaiian or Other Pacific Islander	0	0	0	0	0	0
Persons Reporting Some Other Race	1	1	1	1	2	1
Persons Reporting 2 or More Races	0	0	0	0	0	0
Race Missing	27	—	0	—	27	—
Veteran Status						
Veteran	11	32	31	14	42	16
Non-Veteran	23	68	194	86	217	84
Veteran Status Missing	124	—	179	—	303	—

NOTE: Percentages exclude missing data.

— = Not applicable.

SOURCE: ADSSP National Resource Center analysis of grantee final reports.

A total of 320 persons were served through this grant project: 158 persons with dementia and 162 caregivers. The majority of persons with dementia and caregivers were over 60 years of age and 98% of those served were spouses. Over half of the persons with dementia served were male and 98% of both persons with dementia and caregivers were White, Non-Hispanic. For more detailed information on the persons served, see ***Table B-6***.

The process evaluation used the following methods and data sources: (a) site visits to participating organizations to document baseline organizational characteristics and usual care to caregivers of persons with Alzheimer's disease, with follow-up phone calls, as needed; (b) creation and use of a RE-AIM Tracking Tool for quarterly collection of narrative reports on issues related to implementation, completed by the FMC consultants; (c) review of cost spreadsheets produced by program sites; (d) telephone and in-person interviews with all of the FMC consultants; (e) surveys of FMC consultants and AAA contacts through an electronic survey tool; (f) analysis of Caregiver and Family Experience Surveys sent directly to the Evaluator; and (g) periodic participation in regional calls or project meetings that included updates, conversations with state project staff and others involved in project implementation, and review of state reports, as available.

The FMC assessment was administered to participants at program enrollment; at 4, 8, and 12 months; and every 6 months thereafter. As noted earlier, 162 caregivers completed the intake assessment and 119 completed the intervention. Of those who completed the intervention, 65 completed the 4-month reassessment, 59 completed the 8-month reassessment, and 54 completed the 12-month reassessment. Participants completing reassessments dropped to 26 and 18 for the

18- and 24-month reassessments, respectively. Because of the burden of the lengthy complex assessment, many caregivers declined reassessments. This challenge was addressed in two ways: (1) the assessment was shortened by FMC clinical director, state-level staff, consultants, and the original researchers removing elements that had been added to the original assessment; and (2) the FMC consultants learned the value of the assessment in drawing the caregivers out and establishing a relationship with the caregiver.

The 90AE0323 grant's FMC program showed the following outcomes:

- *Participant Outcomes (Measured Changes in the Person with Dementia or Caregiver)*: Overall, there were statistically significant improvements in the measurements on caregiver depression, stress, relationship burden, and reaction to problem behaviors. Also, although not statistically significant, persons with dementia showed an increase in problem behaviors at 4 months compared with initial assessment, and then a decrease in problem behaviors at 8 months, 12 months, 18 months, and 24 months compared with initial assessment.

- *Social Network Size*: There were statistically significant increases at 4 months, 8 months, 12 months, 18 months, and 24 months in the average number of relatives and friends in the social networks of the persons with dementia and caregivers who received the intervention. The FMC consultants commented that as caregivers built more extensive support networks, the consultants could see a shift in the caregiver and family relationships. It is also notable that the growth in the average size of social networks is maintained and even increases over time. Thus, as caregivers begin to accept help, they learn that they can ask for help as the disease progresses and they need more support.

Infrastructure Development

The program sites that provided FMC for people with dementia and family caregivers under 90AE0323 were a mixture of metropolitan, suburban, and rural areas. Most did not have a specialized service or program that focused on persons with Alzheimer's disease and their caregivers, however, most did have existing services that provided support to any type of family caregiver. Each site had at least one staff person who had been trained on the FMC protocol, and each site provided the necessary resources to this person to maintain fidelity to the program as designed by the original clinician researchers.

The Minnesota FMC Protocol Table in the Operations Manual is the official guide to NYUCI fidelity, and includes all components of the FMC service to be completed for fidelity. The Caregiver Status Sheet, also included in the Operations Manual, verifies fidelity by documenting the progress of the caregiver through each component of the intervention, including ad hoc contacts and reassessments. Although training in the NYUCI is provided by the New York University staff, it was determined that additional strategies were needed to maintain fidelity when applying this intervention outside of a clinically controlled university setting, as follows:

- FMC consultants are required to participate in monthly small group calls for clinical guidance with the clinical director, who is also available to meet with the FMC consultant individually in person, by phone, or by e-mail as needed.

- Quarterly trainings are provided to the FMC consultants by the clinical director and experts in dementia, and attendance at dementia-specific conferences such as the Alzheimer's Association's annual Meeting of the Minds is required.

- The FMC state coordinator has monthly contact with each FMC consultant, supervisory staff, or AAA staff, to discuss progress and to problem solve, bringing in additional resources as needed.

In addition to the NYUCI protocol training, some of the FMC consultants with only a generalist background of caregiver consultant experience received training and education on a variety of topics such as signs and symptoms of Alzheimer's disease, understanding disease stages, strategies and techniques for facilitating groups, understanding family systems theory and family dynamics, effective communication methods and techniques, and care planning and monitoring, among others. Providing the additional training and support was time-consuming and costly and delayed the start of their work with caregivers.

The nature of the intervention presented some challenges to infrastructure development. The FMC consultants needed formal clinical direction, which could not realistically be provided by the small rural host agencies in this translation. This clinical direction had to be provided by a statewide clinical director because these are not typical roles of either the AAA or site supervisory staff. Also, the new FMC sites established under 90AE0323 were small rural voluntary service agencies where salaries are typically low and the agency's future is often uncertain. Some FMC consultants left the program because of agencies going out of business, system reorganizations, or competing job offers with salaries and benefits with which these agencies cannot compete. The project addressed this challenge by relocating FMC consultants to agencies that could provide more stability and higher salaries and benefits. The overall number of FMC consultants was reduced but the amount of FMC consultant time and the number of caregivers to be served remained the same.

Another challenge was implementing an integrated service system where information follows the person. Assessment information was incorporated into Web Referral, the state's care management and data software for MinnesotaHelp.info® and the Senior LinkAge Line® to enable the use of one care management system that is both accessible and meets HIPAA requirements for security.

Sustainability

The original goal of the grant project was to embed FMC consultation within the state's OAA Title IIIE funded caregiver consultation network. Because of limited Title IIIE funding and the skill and education level of funded caregiver consultants needed to deliver FMC with fidelity, the program probably cannot be fully supported with Title IIIE funds. However, AAAs are embedding FMC into ongoing Title IIIB- and E-funded services, and services funded through the Minnesota Community Services/Services Development grant program are also incorporating FMC into their services. Meanwhile, FMC was implemented under the ADSSP grant 90AE0336 until September 2013, and it was also being implemented as part of the state’s Systems Integration project with funding from AoA. Through that grant, the AAAs are building relationships with Minnesota Health Care Homes increasing the potential for ongoing financial support for FMC.

Because there is not sufficient funding or demand for this service in every rural community statewide, the goal is now to have FMC access in a rural population center in each region within a 1-hour travel range for FMC consultants, and to be located in minority communities in the Minneapolis/St. Paul area. At the same time, there is a parallel goal of statewide access to dementia-capable caregiver consultants trained to address the needs of most caregivers for people with Alzheimer’s disease, including those not eligible for FMC such as caregivers who do not live with the person for whom they provide care. Dementia-capable consultants will identify those eligible for FMC and connect them to an FMC consultant.

The original FMC web presence developed as a component of the Minnesota Healthy Aging website has been redesigned and moved to the Minnesota Live Well at Home website, which is targeted to older people, family caregivers, and interested providers. The website includes an overview of the key components of FMC and provides the basics in evidence and anecdotal impact on caregivers and their families in Minnesota. Information is provided on FMC consultants and their locations and on connections to materials and key partnering sites such as the Alzheimer’s Association.

Recommendations From the Project Implementation Team for Future Efforts

It is not recommended that FMC be the first caregiver service offered by any organization. At a minimum, an organization should have some kind of existing caregiver support service to implement the FMC program. This would include (1) at least one part-time staff person already serving as caregiver support staff; (2) familiarity with local resources and services for caregivers (e.g., caregiver support groups, respite programs, memory support groups); and (3) some level of training and structure/process for assessment, care planning, and follow-up.

In terms of one-to-one recruitment, the Minnesota FMC consultants have learned that it is important to describe the FMC program to potential caregiver participants as a *whole family* program—and to convince the caregiver to engage the family early on. Consultants reported that it is often the parent who is reluctant to engage his or her adult children because they are “so busy.” This will continue to be a factor in enrollment that organizations offering this program would need to address. Also, the barrier of eligibility or enrollment criteria requires expansion to offer the program to nonspousal caregivers who are living with the person with Alzheimer’s disease. The AAA representatives assisted with finding additional sources of funding for program site efforts and facilitating technical support. This understanding may be important in the future for continuity. Also, the FMC consultants reported that the peer support and availability of expert consultation was critical to their ability to maintain fidelity to the original intervention.

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Evidence-Based Grant:
New Jersey's Environmental Skill-Building Program for Caregivers of Persons with Alzheimer's Disease and Related Disorders

Introduction

New Jersey's ADSSP grant project was a translation of the Philadelphia evidence-based Environmental Skill-building Program (ESP)[1] into a community setting, using the direct service model referred to as Skills$_2$Care™. In this intervention, occupational therapists provide services to caregivers of persons with Alzheimer's disease and related disorders (ADRD) to help families modify the environment to support daily function of the person with dementia and reduce caregiver burden. Strategies provided reflect simple modifications to the physical environment (e.g., removal of hazardous objects, use of a memory board or daily calendar) and social environment (e.g., communication techniques, cueing and approaches to simplifying everyday tasks) to more resource-dependent recommendations (e.g., installing grab bars or handrails), as well as basic problem solving and stress management techniques.

The intervention is divided into an active and maintenance phase over a 12-month period. The active phase involves up to six 90-minute home visits over a 6-month period, such that caregivers have opportunities to practice strategies independently that are introduced first with the occupational therapist. The maintenance phase occurs between months 6 and 12 and involves three telephone contacts in which the occupational therapist reinforces strategy use, validates caregiver actions, and helps caregivers apply learned skills to newly emerging care problems. As part of the treatment plan, caregivers may be referred to Area Agency on Aging (AAA) programs for the provision of adaptive devices, or to their physician if they score as depressed on an assessment, or for physical therapy if there is a risk of falling, back/neck strain, or injury because of caregiving.

The occupational therapist initiates Skills$_2$Care™ by introducing the goals of the program and conducting an assessment of (1) the home environment for safety and support of daily function and ease of navigation, (2) caregiver concerns and management style, and (3) caregiver-care receiver interactions. During this visit, the occupational therapist introduces basic education about dementia, potential triggers of behaviors, the role of the environment, and the importance of caregiver self-care. Together, the occupational therapist and caregiver prioritize care problems and the occupational therapist instructs caregivers in a basic stress reduction technique (deep breathing). Following the initial assessments, the occupational therapist continues working with the family caregiver at home during the active phase.

The New Jersey Department of Health and Senior Services (DHSS) partnered with the Mercer County Office on Aging—an AAA—to implement the Skills$_2$Care™ intervention, and

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[1] Philadelphia was one of six sites that developed and evaluated a variety of multicomponent interventions for family caregivers of persons with Alzheimer's disease (at the mild or moderate level of impairment) as part of the National Institutes of Health project: Resources to Enhance Alzheimer's Caregivers' Health (REACH I), demonstrating evidence in reducing caregiver burden and enhancing management skills. All of the REACH I interventions were guided by detailed treatment manuals and certification procedures that ensured the interventions were delivered as intended and consistently over time at each site. Follow-up studies, such as this grant project, examine how the interventions might be used in communities through the nation's existing network of health and aging services.

contracted with Rutgers School of Social Work to evaluate the project. The evaluation's two primary objectives were to assess the Skills$_2$Care™ intervention model fidelity and to assess the effects of the intervention on the primary caregiver and the person with ADRD. The Rutgers School of Social Work also evaluated the program's quality and integrity and developed, implemented, and monitored the program's quality improvement measures. In addition, DHSS contracted with Dr. Laura N. Gitlin, Thomas Jefferson University, who was the principal investigator for the evidence-based research on the original intervention, to serve as the consultant for model translation and fidelity.

The grant project's main goal was to translate the ESP intervention to a community setting, demonstrating the benefits of the program. The grant project also sought to increase the capacity of AAAs to implement Skills$_2$Care™ for families of people with ADRD. The project's objectives were to:

- Train and certify occupational therapists to provide the Skills2Care™ intervention.
- Develop linkages with AAA and other local aging services organizations for Skills2Care™ service delivery.
- Create assessment tools and marketing materials.
- Develop and disseminate a cost assessment methodology for program startup and operation costs, and a manual for program replication.

The goal of the grant was to serve 75 caregiver/care receiver dyads. The target population was primary caregivers (family members/friends, excluding paid caregivers) of persons experiencing memory loss, dementia, or Alzheimer's disease, and included minority, limited English-speaking, and economically disadvantaged caregivers. To be eligible for participation in the intervention, the caregiver had to be 18 years or older, living in Mercer County or actively caregiving in Mercer County, and not actively seeking placement in a long-term care setting within the next 6 months. Mercer County was chosen as the translation site because the county's diversity is representative of the state of New Jersey. The grantee recruited different target groups, but was unsuccessful in meeting the grant goal of 75 dyads. At the time of the final report, 45 dyads had enrolled and 22 completed the intervention. Sociodemographic characteristics of the participants are summarized in ***Table B-7***.

A total of 90 persons were served through this grant, including 45 persons with dementia and 45 caregivers (***Table B-7***). The majority of persons with dementia were over 60 years of age and the majority of caregivers were under 60. All participants came from urban areas and the majority of participants were White, Non-Hispanics.

The Mercer County AAA provided traditional marketing and outreach to recruit participants for the intervention, including the distribution of information through the county website, press-releases, and direct mail; through all Mercer County Aging Network providers and satellite offices; at Alzheimer's Association caregiver support groups and other caregiver support groups; and at presentations about environmental skill building given to providers, church-based

Table B-7
Sociodemographic Characteristics of Participants in New Jersey's Environmental Skill-building Program for Caregivers of Persons With Alzheimer's Disease and Related Disorders

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Total	45	—	45	—	90	—
Age						
Under 60	7	16	29	64	36	40
60+	38	84	16	36	54	60
Age Missing	0	—	0	—	0	—
Gender						
Female	26	58	29	64	55	61
Male	19	42	16	36	35	39
Gender Missing	0	—	0	—	0	—
Geographic Location						
Urban	45	100	45	100	90	100
Rural	0	0	0	0	0	0
Geographic Location Missing	0	—	0	—	0	—
Relationship						
Spouse	20	44	20	44	40	44
Unmarried Partner	0	0	0	0	0	0
Child	0	0	20	44	20	22
Parent	20	44	0	0	20	22
Other Relative	5	11	5	11	10	11
Non-relative	0	0	0	0	0	0
Relationship Missing	0	—	0	—	0	—
Ethnicity						
Hispanic or Latino	1	2	1	2	2	2
Not Hispanic or Latino	44	98	44	98	88	98
Ethnicity Missing	0	—	0	—	0	—
Race						
White—Non-Hispanic	39	87	39	87	78	87
White—Hispanic	1	2	1	2	2	2
American Indian or Alaska Native	0	0	0	0	0	0

(continued)

Table B-7 (continued)
Sociodemographic Characteristics of Participants in New Jersey's Environmental Skill-building Program for Caregivers of Persons With Alzheimer's Disease and Related Disorders

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Asian	0	0	0	0	0	0
Black or African American	5	11	5	11	10	11
Native Hawaiian or Other Pacific Islander	0	0	0	0	0	0
Persons Reporting Some Other Race	0	0	0	0	0	0
Persons Reporting 2 or More Races	0	0	0	0	0	0
Race Missing	0	—	0	—	0	—
Veteran Status						
Veteran	1	2	0	0	1	1
Non-Veteran	44	98	45	100	89	99
Veteran Status Missing	0	—	0	—	0	—

NOTE: Percentages exclude missing data.

— = Not applicable.

SOURCE: ADSSP National Resource Center analysis of grantee final reports.

senior groups, and senior advisory councils, among others. To address low recruitment numbers, grant staff increased direct mail outreach and increased in-person meetings with geriatricians/ physicians serving seniors. They also increased local media features and advertised through local cable shows. However, recruitment remained a challenge throughout the project.

Outcomes of Intervention/Program

The main objective of the evaluation was to assess the effects of the intervention on the primary caregiver and the care receiver using methods consistent with the Philadelphia REACH I study. The evaluators conducted baseline interviews and post-intervention interviews over the phone with caregiver participants. They also conducted an occupational therapist focus group to assess the impact of the intervention. The intended outcomes for caregivers and care receivers included reduced distress with troublesome behaviors, reduced need for assistance from others, improved mood, and enhanced mastery and self-confidence for the caregiver; and reduced frequency of problem behaviors and slowed rate of functional decline for the person with ADRD. The expected outcomes for the occupational therapists were that each felt adequately prepared to provide Skills$_2$Care™ and were able to implement the program successfully.

The evaluator adapted a battery of measures from the Philadelphia REACH I study into a detailed questionnaire administered by phone to caregivers at baseline (i.e., immediately after enrollment into the program) and at 6 months after the intervention began (i.e., immediately after the active phase was complete). Measures included the Perceived Change Index (caregiver well-being); Dementia Management Strategies Scale (self-appraisal of ability to provide care); Task Management Strategy Index (use of positive caregiving strategies); Revised Memory and Behavior Problem Checklist (disruptive and memory-related behaviors); Subjective Burden Survey (caregiver distress with memory-related behaviors, disruptive behaviors, activities of daily living (ADL) assistance, and instrumental activities of daily living (IADL) assistance); Functional Independence Measure (mobility domain or ADLs); and Index of IADL Dependence.

The evaluation of caregivers who completed the active phase of the intervention showed alignment with previous research on the program. Because the number of respondents was very small, the lack of statistical power prevented the use of traditional statistical methods to conduct group comparisons. Comparing baseline and 6-month scores:

- Caregivers assisted the care receiver more frequently with IADLs and with more IADL items. However, there was a decrease in the level of subjective burden from assisting with IADLs.

- Caregivers assisted with the same number of ADLs, but showed a decrease in level of subjective burden from helping with ADLs.

- Caregivers showed a positive gain in well-being.

- Caregivers reported more behavioral problems than at baseline, but experienced less subjective burden related to these behavioral problems.

- Caregivers reported increased level of confidence in dealing with behavioral problems and caregiving issues, as measured by improved results for 13 of 14 confidence items.

- There was no noticeable difference between baseline and post-intervention scores for caregivers' self-appraisal of ability to provide care or the use of positive caregiving strategies.

- Caregivers made overwhelmingly positive comments about the importance and helpfulness of the program and also praised the occupational therapists.

To assess the impact of the program on the trained occupational therapists, the evaluator held a focus group with interventionists. Overall, the occupational therapists felt that Skills$_2$Care™ was well run and identified several important strengths, for example, the support provided by the larger program team, the availability of information on resources for caregivers and those with ADRD, and the connection to the Mercer AAA. They also made a positive assessment of the training and overall felt prepared to begin the intervention.

The greatest challenge in the data collection phase was reaching caregivers and conducting interviews soon after registration for Skills$_2$Care™. Because of the demanding nature of their lives, it was difficult for some caregivers to find a convenient time to participate in the interview and they occasionally needed to cancel scheduled interview calls.

Infrastructure Development

Skills$_2$Care™ builds on the basic knowledge and skills of occupational therapists; however, it is unconventional compared to traditional occupational therapy practice and requires training in its assessments, protocols, client-centered care models, and treatment principles. Training topics center on dementia and understanding challenging behaviors; the nature of caregiving and cultural considerations; core treatment principles (client-centered, cultural competency, tailoring/customizing, active learning techniques, problem-solving oriented); and program components and delivery procedures. Occupational therapists are certified in Skills$_2$Care™ to provide hands-on education to families to enhance their abilities to manage caregiving day to day. Therefore, Skills$_2$Care™ requires a high level of clinical reasoning, face-to-face practice time, and follow-up coaching opportunities during the training and certification process.

Four occupational therapists were identified for the grant project through recruitment efforts conducted by the executive director of Mercer County Office on Aging and the clinical coordinator of the Skills$_2$Care™ program. All four met the following criteria: licensed occupational therapists, a minimum of 2 years of geriatric experience, and a history of home-based therapy experience. The occupational therapists completed 8 hours of assigned readings and 8 hours of web-based asynchronous training (lectures and active learning exercises) to prepare for the face-to-face training workshop. The clinical coordinator of the Skills$_2$Care™ program conducted the 2-day workshop and provided therapists with a manual of procedures, guiding scripts, treatment documentation forms, and comprehensive training through active learning. Therapists practiced assessment, intervention delivery, and documentation completion. Administration procedures were introduced such as the referral process, team communication, access to supplies, and use of resources (specifically the array of services provided by Mercer County's Office of Aging).

One of the challenges that occurred in the Mercer County project was a time lapse between Skills$_2$Care™ training and program delivery because of delayed Institutional Review Board approval (caused by DHSS departmental reorganization). To address this problem, a booster training session was supplemented to review, reinforce, and practice intervention protocols and documentation with the therapists prior to working with their first caregiver. In addition to the training, the occupational therapists participated in five group coaching sessions with the clinical coordinator (via teleconference).

However, because of the chaotic nature of caregivers'/care receivers' lives and relationships, it was sometimes challenging to perform the intervention exactly as prescribed in the order prescribed. Also, the dosage and duration of the Skills$_2$Care™ intervention is not typical of the traditional homecare provision of services (e.g., treatment provided two or three times per week). In particular, one of the therapists who worked for a home health agency had a difficult time interweaving periodic Skills$_2$Care™ sessions within her often busy, tightly scheduled patient caseload.

Mercer AAA hoped to build a strong core group of trained certified providers to support the delivery of the Skills$_2$Care™ intervention in Mercer and surrounding counties. Although the initial interest in the program was strong, agencies had difficulty understanding the service. The intervention activities were not viewed as part of the routine services offered to clients in the way that Medicare, Medicaid, and other services are treated and support for the intervention was lacking.

Sustainability

The grant project achieved the overall goal, which was to translate evidence-based research into an aging network service delivery model serving caregivers of persons with ADRD and sustainable through Title IIIE funding. Project activities will be sustained by the translation site, the Mercer County AAA, which is taking the steps necessary to embed Skills$_2$Care™ into its service delivery system through its 2013 Area Plan Contract.

In addition, Thomas Jefferson University will continue to support the trained occupational therapists through resources and technical assistance as a condition of the license agreement, and Rutgers University has expressed interest in conducting a focus group with the caregivers who participated in the project. Rutgers staff and the Mercer AAA director are in discussions around this.

Recommendations for Future Efforts From the New Jersey Project Team

Caregiver recruitment and occupational therapist participation remained a challenge throughout the project. As the New Jersey aging network and other states move forward with the implementation of Skills$_2$Care™, providers of occupational therapist services who partner in the program must treat the intervention as a routine part of the agencies' services. Providers should give as much weight and importance to the intervention as they give to Medicare B, Medicaid, and other funded services.

To successfully embed Skills$_2$Care™ within the traditional homecare therapist's schedule, a close working partnership between key stakeholders (occupational therapist, dedicated agency-based supervisor and Skills$_2$Care™ clinical coordinator) is required. The agency-based supervisor must allocate time within the therapists' schedule to deliver Skills$_2$Care™ as per protocol. Support and commitment from agency administration is critical to ensuring full implementation. Also, an important component of the translation is training that orients occupational therapists to AAAs, including its role in supporting caregiving families, staff, resources, and expectations for referral families when issues arise.

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Evidence-Based Grant:
North Carolina Resources For Enhancing Alzheimer's Caregiver Health (Reach) II Translation Project

Introduction

The North Carolina (NC) Division of Aging and Adult Services, in partnership with Area Agencies on Aging (AAAs); Mecklenburg County Department of Social Services; the Duke Family Support Program, University of North Carolina at Chapel Hill; and the University of Michigan launched the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II program in 2008. The intervention was selected by North Carolina because it had been carefully developed, refined and tested over a 10-year period in various sites across the nation.[1]

The overall goal of the REACH II intervention is to enhance the ability of caregivers to manage stress, depression, and burden; improve caregiver skills for self-care and healthy behaviors; help caregivers make better use of social support networks; reduce risk for care recipients; and increase the capacity for family care at home. REACH II is delivered by trained interventionists to dementia caregivers and their care recipients through 12 in-home visits and telephone calls over a 6-month period. The seven core intervention components include (1) risk assessment, (2) information and training on Alzheimer's disease and related dementias, (3) guidance and encouragement in physical self-care and safety, (4) strategies for managing challenging behaviors, (5) optional therapeutic phone sessions, (6) tips on how to access social support and community resources, and (7) techniques for relaxation and stress management. The NC interventionists ensured fidelity in the program implementation while adapting it for cultural sensitivity and contextual relevance.

The objectives of the NC REACH II translation project included the following:

- Train seven interventionists across nine AAA regions on the REACH II model.
- Deliver NC REACH II intervention services through five program sites serving 23 counties.
- Enhance existing infrastructure for ongoing sustainability and maintenance of evidence-based programs in North Carolina.
- Ascertain program benefit for targeted populations and analyze cost-effectiveness of the intervention.

The targeted populations included rural, low-income, minority caregivers of persons with dementia. A total of 68 participants were served through the project: 34 persons with dementia and 34 caregivers. Twenty of the persons with dementia served through the project (59%) were female and 30 of the caregivers served (88%) were female. The majority lived in a rural area and

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[1] Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., Gitlin, L. N., Klinger, J., Koepke, K. M., Lee, C. C., Martindale-Adams, J., Nichols, L., Schulz, R., Stahl, S., Stevens, A., Winter, L., & Zhang, S. (2006). Resources for Enhancing Alzheimer's Caregiver Health (REACH) II investigators. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine, 145*(10), 727–738.

13 of persons with dementia (38%) and 14 of caregivers (41%) were African American (see ***Table B-8***.

Table B-8
Sociodemographic Characteristics of Participants of North Carolina's NYUCI Evidence-Based Expansion

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Total	34	100	34	—	68	100
Age						
Under 60	1	3	12	35	13	19
60+	33	97	22	65	55	81
Age Missing	0	—	0	—	0	—
Gender						
Female	20	59	30	88	50	74
Male	14	41	4	12	18	26
Gender Missing	0	—	0	—	0	—
Geographic Location						
Urban	14	41	14	41	28	41
Rural	20	59	20	59	40	59
Geographic Location Missing	0	—	0	—	0	—
Relationship						
Spouse	19	56	19	56	38	56
Unmarried Partner	0	0	0	0	0	0
Child	0	0	12	35	12	18
Parent	12	35	0	0	12	18
Other Relative	3	9	3	9	6	9
Non-relative	0	0	0	0	0	0
Relationship Missing	0	—	0	—	0	—
Ethnicity						
Hispanic or Latino	0	0	0	0	0	0
Not Hispanic or Latino	34	100	34	100	68	100
Ethnicity Missing	0	—	0	—	0	—

(continued)

Table B-8 (continued)
Sociodemographic Data on Participants of North Carolina's NYUCI Evidence-Based Expansion

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Race						
White—Non-Hispanic	19	56	17	50	36	53
White—Hispanic	0	0	0	0	0	0
American Indian or Alaska Native	2	6	3	9	5	7
Asian	0	0	0	0	0	0
Black or African American	13	38	14	41	27	40
Native Hawaiian or Other Pacific Islander	0	0	0	0	0	0
Persons Reporting Some Other Race	0	0	0	0	0	0
Persons Reporting 2 or More Races	0	0	0	0	0	0
Race Missing	0	—	0	—	0	—
Veteran Status						
Veteran	0	0	0	0	0	0
Non-Veteran	0	0	0	0	0	0
Veteran Status Missing	34	—	34	—	68	—

NOTE: Percentages exclude missing data.

— = Not applicable.

SOURCE: ADSSP National Resource Center analysis of grantee final reports.

Outreach strategies used the existing Alzheimer's disease supportive services network, including the Alzheimer's Association, NC's Caregiver Alternatives to Running on Empty (C.A.R.E.) Project, the AAAs, Aging and Disability Resource Centers, and the Mecklenburg County Department of Social Services. Participant recruitment methods included dissemination of program flyers and brochures at health fairs and public awareness events. Also, informational packets were mailed to community centers, memory assessment clinics, physicians, pharmacies, hospitals, churches, senior centers, provider agencies, and other key organizations serving the target population.

The goal of the grant was to serve 100 participants. Although the project was successful in reaching its target population (15% of caregivers enrolled were below the federal poverty level poverty line, 41% were African American, and 53% were rural), it was not successful in meeting target numbers of participants. A total of 34 dyads (persons with dementia and their caregivers) were enrolled in the program; of these 27 dyads completed the intervention.[2]

Project C.A.R.E. was intended to be a primary recruitment source, serving 19 counties and already working with caregivers of persons with dementia. However, Project C.A.R.E. was administratively moved twice during the grant, negatively affecting recruitment and therefore enrollment rates. To increase the number of families served, enrollment was opened up from only existing Project C.A.R.E. clients to all potential clients in the REACH II service areas. This strategy included outreach to additional groups, such as Project C.A.R.E. waiting list clients, Family Caregiver Support Program clients, and clients from the North Carolina Home and Community Care Block Grant In-Home Aide program.

Additional barriers to caregiver recruitment included the level of commitment to REACH II, the length of the intervention, and caregiver resource materials. NC REACH II required a face-to-face contact twice a month—2 to 3 hours per visit—for 6 months, while the resource materials provided in the "Caregiver Notebook" were perceived as overwhelming to many of the caregivers and noted as being difficult to navigate.

Outcomes of Intervention/Program

All outcomes were measured by interviewing caregiver participants at baseline, prior to the intervention, and at 6 months, after the completion of the program. Measures included the Zarit Burden Scale, PHQ-9 Depression Survey, and Caregiver Survey and Caregiver Risk Appraisal Questionnaire. In addition, a caregiver satisfaction survey was administered at the end of the intervention. The survey assessed satisfaction with the types and quality of services provided, and the information provided by the interventionist at each session.

Caregivers who participated in the NC REACH II program were highly satisfied with the intervention and experienced an overall improvement in well-being. At the conclusion of the project, a total of 24 caregivers (those who had completed the intervention and the post-test assessments) showed an improvement in satisfaction with social supports, a significant (33%) reduction in depression, and a significant (17.4%) decrease in caregiver burden and stress. Caregiver and care receiver risk in the domains of health, safety, well-being, and financial management was also evaluated, the outcome of which was a significant (20%) reduction in caregiver risk. Using the Memory and Behavior Problems Checklist administered at the end of the intervention to assess care recipients' behavior and the caregivers' appraisal of the severity of the behavior, 78% of reported care receiver behaviors post-intervention either stayed the same or decreased in severity.

In addition to individual outcomes, REACH II increased state capacity to effectively support families caring for people with dementia at home. NC REACH II was implemented in 36 counties across the state through four main sites.

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[2] Seven of the 34 caregivers dropped out prior to completing the full intervention because of caregiver illness, death or placement of care recipient, or feeling too "overwhelmed" (e.g., marital difficulties, financial problems, or work schedule).

Infrastructure Development

The implementation of the NC REACH II intervention began in September 2008 with the training of coaches and Project C.A.R.E. interventionists and the development of the procedures, data tracking methods, marketing materials, and other components of starting up the intervention at each location. The enrollment of the first caregivers began on September 1, 2009. NC REACH II was proposed to focus on 23 counties located in 9 of 16 AAA planning and service areas. However, the program was expanded to 36 counties to increase recruitment opportunities. Partnerships with the NC Division of Aging and Adult Services for local implementation included the following:

- Mecklenburg County Department of Social Services, located in Charlotte, NC, provides all home and community-based services under the Older Americans Act. Mecklenburg County has a proportionately high percentage of low-income minority older adult residents and is one of the most densely populated urban counties in North Carolina.

- Park Ridge Hospital consists of rural counties in western North Carolina.

- Lumber River Council of Governments AAA administers Project C.A.R.E. in six rural southeastern North Carolina counties.

- Mid-East Commission AAA administers Project C.A.R.E. over a 10-county area of rural northeastern North Carolina.

Fifteen interventionists were employed within the four sites, although their total hours working on the NC REACH II intervention equaled four full-time positions. Four additional staff members were trained as coaches for the interventionists. Each REACH II interventionist attended an initial 3-day orientation and training workshop; the curriculum included reading materials, structured role play, and practice opportunities. The training focused on seven areas: (1) Alzheimer's disease and related dementias, (2) cultural sensitivity, (3) active skills training on relaxation techniques for depression, (4) making the physical environment safe, (5) improved physical self-care, (6) assessing social support, and (7) writing behavioral prescriptions for managing activities of daily living and problem behaviors. Each interventionist received a comprehensive training workbook, the Intervention Manual. Weekly coaching sessions with interventionists were offered by REACH II Intervention Coaches to provide fidelity assessment, aid in implementation, and collect data; and the Division of Aging and Adult Services conducted monthly technical assistance conference calls and meetings during the first 10 months of implementation.

NC REACH II was rolled out in successive stages (years 2009 and 2010) in three regions in the state. As part of the process evaluation, mid-course assessments were conducted in Year 1 and in Year 2 of the intervention. Interventionists who were part of the first implementation cohort participated in both years of the mid-course assessments and were joined by a new wave of interventionists in the second year. The purpose of the assessments was to serve as check points to review the implementation process, build on demonstrated strengths, identify problem areas and needs for adaptation to better fit service delivery, and modify operations based on what was not working. The mid-course assessments uncovered a broad range of unanticipated issues regarding program adaptation including difficulty in scheduling appointments, need for more respite time, and need to reduce amount of paperwork for both the interventionists and participants.

Assessments by the six interventionists/coaches in the western part of the state indicated a need to focus primarily on tailoring pre-intervention training to discuss the family consultant role and flexibilities within the timing and delivery of program content, gearing the intervention training to skill and experience levels of the trainees, streamlining the family consultant and caregiver intervention guides and tools, and shifting the mandatory weekly coaching sessions to "as needed." In addition, the interventionists/coaches recommended reducing the number of sessions (12) and length of time (6 months) to attract more caregivers, opening program enrollment to related family support programs or caregiver support groups, and tailoring recruitment materials according to caregiving characteristics (e.g., retired versus working; caring for a relative with mild, moderate or severe dementia).

Sustainability

In July 2010, the C.A.R.E. project received a new recurring state appropriation of $100,000 for respite services that were in part used for REACH II participants. Also in 2010, North Carolina received an additional two grants from the U.S. Administration on Aging to fund a modified version of REACH II, called REACH OUT, which continued until mid-2013. Long-term sustainability for REACH OUT is and will be further explored in conjunction with Project C.A.R.E. because of the overlap of trained/qualified interventionists. Project C.A.R.E. requested an additional $500,000 in recurring state appropriations beginning in the 2013 legislative session. If approved, the REACH intervention will continue to be provided to interested and eligible caregivers. However, the economic and political climate are extremely challenging during this biennium, and without additional funding, only limited sustainability will be possible.

Recommendations for Future Efforts From the North Carolina Project Team

Recruitment and retention of caregivers for a 6-month intervention that requires 12 meetings is difficult, and costly. Generally, this project found that dementia caregivers often seek help once they are in a crisis situation. These situations include needing respite care and intense case management. Many caregivers envision an intense intervention as additional tasks added to an already heavy burden. The need for respite care often overshadows the long-term needs of dementia caregivers. However, caregivers who are participating in support groups are more inclined to fulfill the time commitment of an intervention like REACH II, as they are seeking to improve their caregiving skills, reduce their stress, and seek outside resources to support their caregiving role.

Evidence-Based Grant:
Reducing Disability in Alzheimer's Disease in Ohio

Introduction

Reducing Disability in Alzheimer's Disease (RDAD) is an evidence-based program designed for both the person with a diagnosis of Alzheimer's disease and his or her primary caregiver, which was created and tested in a randomized-controlled trial.[1] The RDAD program is an in-home intervention that combines a gentle exercise program for the person with dementia and a problem behavior management training for the family caregiver. The program involves 12 one-hour sessions conducted over 3 months, with monthly follow-up over an additional 3 months. The exercise component consists of strength, balance, and flexibility training with endurance activities—such as walking or other aerobic activity—also encouraged. The caregiver problem behavior management training includes (1) maximizing cognitive functioning, (2) using the ABC (Activator—Behavior—Consequence) technique to problem-solve difficulties, (3) reinforcing pleasant activities, and (4) enhancing caregiver resources and skills.

The ADSSP grant project, RDAD in Ohio, was a 3-year partnership between the Ohio Department of Aging, the Benjamin Rose Institute on Aging, and four of the Ohio Alzheimer's Association Chapters. The overall goal of the grant was to translate the original RDAD program in a community-based setting and then expand the program to other regions within Ohio. Specific objectives included developing the necessary training, support infrastructure, and model to implement the program statewide and replicate it nationally and internationally. Throughout the project, all the partners regularly consulted with the original researcher of RDAD, Linda Teri, PhD, who helped to guide the project team on maintaining fidelity to the original project while also providing guidance to the agencies as they implemented the program.

The Ohio Department of Aging provided guidance and technical assistance and serving as a conduit among team members and to the broader aging network, while the Alzheimer's Association Chapters delivered the RDAD program to persons with dementia and their caregivers. The Northwest Ohio Chapter, covering a 24-county service area shared with three Area Agencies on Aging (AAAs), served as the pilot site and began offering the program in May 2009. Three other chapters (Central Ohio Chapter, Greater East Ohio Area Chapter and Miami Valley Chapter) began implementing the program in April 2010. The Benjamin Rose Institute on Aging provided leadership on the evaluation component of the project, and provided education and technical assistance to the Alzheimer's Association Chapters, emphasizing the importance of fidelity and adherence to evaluation procedures.

The RDAD in Ohio program targeted persons who have a dementia-related diagnosis, live in the community, were ambulatory, and had an actively involved family caregiver. The grant goal was to serve 450 caregiver/care receiver dyads. More than 550 families expressed initial interest in the program and 404 dyads enrolled. Some of those that did not enroll were deemed ineligible because of physical limitations or because they were not residing in the

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[1] Teri, L., Gibbons, L. E., McCurry, S. M., Logsdon, R. G., Buchner, D. M., Barlow, W. E. et al. (2003). Exercise plus behavioral management in patients with Alzheimer disease: A randomized controlled trial. *Journal of the American Medical Association, 290*(15), 2015–2022.

community. Others did not enroll after learning more about the program. This necessitated more time spent on recruitment than anticipated, and also meant that staff resources were often used helping noneligible families find other programs and services that would meet their needs. Sociodemographic characteristics of the enrolled participants are summarized in ***Table B-9***.

Table B-9
Sociodemographic Characteristics of Participants in Reducing Disability in Alzheimer's Disease in Ohio

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Total	404	—	404	—	808	—
Age						
Under 60	12	4	89	27	101	15
60+	320	96	243	73	563	85
Age Missing	72	—	72	—	144	—
Gender						
Female	166	50	241	73	407	61
Male	166	50	91	27	257	39
Gender Missing	72	—	72	—	144	—
Geographic Location						
Urban	282	90	282	90	564	90
Rural	31	10	31	10	62	10
Geographic Location Missing	91	—	91	—	182	—
Relationship						
Spouse	215	65	216	65	431	65
Unmarried Partner	2	1	2	1	4	1
Child	0	0	95	29	95	14
Parent	95	29	0	0	95	14
Other Relative	9	3	9	3	18	3
Non-relative	10	3	9	3	19	3
Relationship Missing	73	—	73	—	146	—
Ethnicity						
Hispanic or Latino	1	0	1	0	2	0
Not Hispanic or Latino	297	100	301	100	598	100
Ethnicity Missing	106	—	102	—	208	—

(continued)

Table B-9 (continued)
Sociodemographic Characteristics of Participants in Reducing Disability in Alzheimer's Disease in Ohio

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Race						
White—Non-Hispanic	302	92	302	92	604	92
White—Hispanic	0	0	0	0	0	0
American Indian or Alaska Native	0	0	1	0	1	0
Asian	1	0	2	1	3	0
Black or African American	24	7	23	7	47	7
Native Hawaiian or Other Pacific Islander	0	0	0	0	0	0
Persons Reporting Some Other Race	2	1	1	0	3	0
Persons Reporting 2 or More Races	0	0	0	0	0	0
Race Missing	75	—	75	—	150	—
Veteran Status						
Veteran	81	37	31	14	112	25
Non-Veteran	140	63	194	86	334	75
Veteran Status Missing	183	—	179	—	362	—

NOTE: Percentages exclude missing data.

— = Not applicable.

SOURCE: ADSSP National Resource Center analysis of grantee final reports.

A total of 808 persons were served in this Ohio grant, including 404 persons with dementia and 404 caregivers ***(Table B-9)***. The majority of persons with dementia and caregivers served were over 60 years of age. Seventy-three percent of caregivers were female while the persons with dementia served were evenly split between female and male. Most participants lived in urban areas and the majority of participants were spouses. Thirty-seven percent of persons with dementia and 14% of caregivers were veterans.

Referral sources were vital to the success of the program. The Alzheimer's Association Chapters promoted the program through newsletters, support groups, press releases, and at respite and early-stage memory programs. In addition, the Northwest Ohio Chapter contacted physician offices as part of its recruitment efforts, and the Greater East Ohio Area Chapter focused on partnering with home care agencies and continuing care and independent living communities. Some chapters worked with local AAAs to promote the program. At the state level, the Ohio Department of Aging helped to promote the program via television, specialized articles on the department website, and at meetings with AAAs, Veterans Affairs, and other organizations.

Often there were delays in receiving referrals because of administrative issues within the chapters or other organizations making the referral, or there were delays between the time the referral was received and the initiation of the program. Contributing factors included (a) heavy workloads; (b) numerous referrals being received within a short time period with only limited staff to offer the program; (c) staffing issues because of staff transitions, illnesses, or vacations; and (d) capacity issues within the Alzheimer's Association Chapters.

Outcomes of Intervention/Program

As with most program translations, the RDAD in Ohio project evaluation did not include a "control" or comparison group. Thus, data on the Ohio families cannot be simply compared to the original RDAD randomized-controlled trial.

For the RDAD in Ohio evaluation, data were collected from the Alzheimer's Association Chapters, participating families, and trainers (i.e., implementation staff) in the form of interviews, screening questions, assessments, surveys, and program utilization paperwork. Participant assessments were completed at baseline, 3 months (at the conclusion of the training program), and 6 months (at the conclusion of the 3-month follow-up period). A program adherence form, referred to as the Treatment Compliance Measure, was completed by trainers after each RDAD session. Information from these forms provided a description of how the 12 core program sessions were offered and captured the extent to which families completed program "homework" between sessions.

Measures from the original RDAD randomized-controlled trial, which included physical performance assessments, self-report through caregiver proxy, and program adherence measures, were used in the RDAD in Ohio replication. However, to facilitate the translation to a community setting, slight differences in data collection methods and measures were required. For example, in the original randomized-controlled trial, interviewers blinded to the intervention and control group assignment were used to conduct assessments of the persons with dementia and to interview the caregivers. In the Ohio replication, it was not cost-effective to send both an interviewer and a trainer to the participating families; therefore, it was decided that trainers would conduct the assessment of the person with dementia, and caregivers would be given a survey to complete on their own and return to the evaluation team.

The original RDAD randomized-controlled trial focused primarily on outcomes related to the care receiver's physical health and function and the affective status of the care receiver and caregiver (i.e., depression). For the RDAD in Ohio evaluation, the focus was extended to also explore outcomes on caregiver unmet need, health strain, and other domains. Paired-samples t-tests were conducted to determine whether there was a change in 10 outcomes between baseline, 3 months, and 6 months. Program satisfaction results and trainer perspectives suggest that families were happy with the program and with the trainers, and that there was a benefit in participating for both the person with dementia and the caregiver. However, the evaluation did not find any statistically significant improvements in physical, behavioral, or emotional outcomes for either persons with dementia or caregivers. In fact, results indicated that the physical functioning, role limitations, and IADL limitations of persons with dementia worsened over time. But these declines were minimal and might be expected in a population of persons with dementia regardless of involvement in an exercise-based program. However, the participating caregivers did show a decrease in their number of unmet needs, from 11.19 unmet needs at baseline to 7.38 unmet needs at 3 months, and decreased further to 5.89 unmet needs at 6 months. This was an area unexplored in the original RDAD randomized-controlled trial, but statistically and substantively is a positive finding in the translation.

Of the 404 caregiver/care receiver dyads who began the Ohio replication program during the grant period, 110 left the program before completing the core sessions (i.e., before Session 12 at 3 months). The primary reason for leaving the program in the first 3 months was the health of the person with dementia (39 cases), and the next most common reason was noncompliance (23 cases). Examples of noncompliance included the person with dementia not doing the exercises and the caregiver not participating in sessions. A further 15 persons with dementia left because of placement, while caregiver health (10 cases) and caregiver burden (9 cases) were the next most common reasons for leaving the program. Four dyads left because they felt the program was no longer beneficial, three dyads left because of relocation, and three persons with dementia died.

The analysis of the survey-based measures indicated that caregivers who were more depressed at baseline were 1.12 times more likely to stay in the program. In addition, dyads where the care receiver lived with the caregiver were 3.23 times more likely to stay in the program. Using the baseline assessment-based measure, the analysis indicated that care receivers with better balance were 1.27 times more likely and those with less cognitive ability were 1.03 times more likely to stay in the program. These findings should be considered with additional replications as a method for targeting the program to families who are most likely to remain involved for at least 3 months.

Infrastructure Development

The aging network in Ohio has a strong history of partnering to create and advance programs and supportive services for individuals living with Alzheimer’s disease and related disorders. Four Alzheimer’s Association Chapters delivered the RDAD program to persons with dementia and their caregivers. Each chapter had a designated program administrator who oversaw recruitment, screening, family assignment, and trainer supervision. In addition, the program administrator participated in planning and trouble-shooting calls with program administrators at other chapters and with the Project Leadership Team.

Regular monitoring calls were held with the interventionists and program evaluators and coordinators to ensure program fidelity and troubleshoot any issues. To complement the original Intervention Manual, an additional manual was created that guides program recruitment, screening, training, data collection, and program administration, and provides replicable templates and forms. Structured 1-day initial and 1-day refresher training for trainers and were also developed, with an additional half-day training session required for program administrators who oversee the program at chapters.

Two initial trainings were held to prepare Alzheimer’s Association staff as RDAD trainers. Periodically throughout the grant period, because of staff attrition and changes, additional initial RDAD trainings were held. The training materials and tools used were consistent with previous trainings; however, each time these trainings were held, evaluations from previous trainings were reviewed and revisions were made to enhance and improve the training.

Challenges associated with training included the following: There were a limited number of master trainers, resulting in delays to program services, and some RDAD trainers needed additional training on the basics of dementia. Fortunately, the Alzheimer's Association Chapters have a standardized curriculum, which was used for this purpose. Also, because of the large distances between sites, coordination of training was complex. The Project Leadership Team was able to assume responsibility for many of the RDAD trainings in Ohio and this helped to train additional RDAD staff in a more efficient manner.

A further challenge was that an exercise consultant was needed to provide technical assistance to the RDAD chapters because no staff members had formal education and training in exercise science. Initially, an RDAD exercise consultant was available from the University of Washington, who worked alongside Dr. Teri. However, as the program continued, it was recognized that a local exercise consultant was needed.

A user-friendly, easily accessed database tracking system had to be created, and several revisions were made after it was launched. This type of database was new for many of the chapters and inputting data was a challenge. Additional RDAD training was needed to increase the understanding and comfort level of the program administrators so that data could be inputted regularly. At times, chapters did not enter the data in a timely manner.

The unique characteristics of each chapter meant that each faced its own individual challenges in adopting RDAD practices that fit within its organizational norms. For instance, one of the chapters did not make home visits to families prior to the RDAD grant implementation. As a result, the chapter had to examine many of the policies, procedures, and practices it had in place and had to consider safety and liability issues. Different chapters also have different levels of knowledge about evaluation and differing resources for addressing problems that arise. The RDAD Project Leadership Team worked with each chapter to help integrate the RDAD program into the chapter and to address the unique nuances which arose.

As the pilot chapter received more referrals and interest grew in the program, the original 3.5 FTE (full-time equivalent) trainers providing the service were not sufficient. Therefore, two additional staff members were trained. This trend continued as the RDAD program expanded and the additional RDAD chapters also needed to increase staffing hours because of demand from families who wanted to enroll in the program.

The wide variation in the characteristics, diagnosis, and needs of the families that enrolled in the program was another challenge. Trainers had to be flexible, creative, and willing to adapt to the wide array of age ranges, various stages of dementia the individual was encountering, the different diagnoses of dementia (e.g., Alzheimer's disease, fronto-temporal dementia, vascular dementia) and comorbid conditions such as heart disease, cancer, and diabetes. These factors created the need for different approaches to the ABC behavior modification technique and for exercise modifications. Regular supervision was very helpful for the RDAD staff to be able to share experiences, brainstorm ideas, and problem solve as challenges with the implementation of the program emerged. In addition, trainers also began using additional resources (e.g., information and referral lists for home care providers) and educational materials (e.g., Alzheimer's Association informational brochures, books) with RDAD families in an attempt to increase their coping and behavior management skills.

Sustainability

In the short term, the program is being fully sustained through a second ADSSP grant to Ohio from the Administration on Aging (RDAD Expansion and Advancement), which has provided funding to (1) continue the project, (2) expand the RDAD program to additional areas of the state of Ohio, and (3) test alternative delivery models. Stakeholders from Ohio and the original RDAD researcher have discussed program ownership, possible funding sources, and future steps for replication and program distribution, but consensus on these had not been achieved by the final grant report. It is expected that clarity on the aforementioned issues were reached by August 2013, which is the end date for the RDAD Expansion and Advancement grant.

It is uncertain whether the program will be continued after the expansion grant because all partnering agencies stressed difficulties sustaining the program beyond the funding period. However, the chapters are interested in exploring alternative models of delivering this program to determine whether it can be offered in a more cost-effective way. Possible avenues for continuing the work include securing additional funding through local and state entities, reimbursement mechanisms (although a fee-for-service model would be challenging because it is already difficult to recruit families when the program is free), and the agencies' capacity to further absorb the program into current service menus.

Recommendations From the Project Implementation Team for Future Efforts

Further evaluation is needed to understand the impact of the program on (1) physical functioning of the person with dementia, (2) caregiver burden and strain, and (3) additional quality of life indicators such as hospital visits and healthcare expenses. Also, analysis should be conducted to determine whether there are an ideal number of sessions when the ABC cards and exercises are used, because for certain participants in the RDAD in Ohio intervention too much use of the ABC card or exercises were related to poor outcomes; therefore, it should not be assumed that "more" is always better. In addition, using findings from this replication, the program can be targeted to families who are most likely to remain involved for at least 3 months. For example, those who were most likely to stay in the program included caregivers who were more depressed at baseline, dyads where the care receiver lived with the caregiver, and care receivers with less cognitive ability.

Maintenance of program outcomes for families was seen in two ways. For caregivers, there was a distinct decrease in the number of unmet needs from 11 unmet needs at baseline to 7 at 3 months to just less than 6 at 6 months. This suggests that families gained from the program and that it involves a long-term, positive impact. Unfortunately, the survey and assessment data did not reveal any long-term (6 months) outcomes showing improvement for persons with dementia; however, declines are expected among people with dementia. Through the 6-month survey caregivers agreed with statements that the exercises helped the care receiver's physical and emotional health.

RDAD is time and labor intensive, and therefore relatively expensive. Cost savings could be explored by examining program delivery methods while maintaining fidelity to the original randomized control trial. For example, because frequent home visits are expensive, RDAD trainers were encouraged to group RDAD home visits as much as possible so that they were visiting families on the same days within certain towns, cities, counties, or even zip codes. This was not always possible but it did help with increasing efficiency in offering the program. In addition, it may be a cost-effective measure to determine whether the frequency or number of visits could be reduced to minimize expenses as much as possible.

Evidence-Based Grant:
Oregon's STAR-C Project

Introduction

Oregon's grant project implemented a translation of the evidence-based behavioral intervention called STAR-Caregivers (STAR-C),[1] a program that aims to decrease depression and anxiety in individuals with Alzheimer's disease and their family caregivers. Developed by researchers at the University of Washington's School of Nursing Northwest Research Group on Aging, STAR-C in its original format consists of eight weekly in-home sessions followed by four monthly telephone calls. During the home visits, consultants teach caregivers to understand challenging behaviors and provide problem-solving strategies and the value of enjoying pleasant events. The consultants also provide basic information on Alzheimer's disease and community support resources. The follow-up of four monthly calls allows the STAR-C consultant to provide support and encouragement in sustaining the approaches adopted during the intervention. In the original research, STAR-C resulted in improvements in depression and lessened caregiver burden, and reduced the frequency and severity of behavior problems.

Oregon's translation made changes to the initial protocol by relying on existing case managers rather than master's-level mental health providers or nurses to conduct the intervention. Most case managers had at least a bachelor's degree and experience working with low-income older adults and people with disabilities, but prior dementia-specific training was not required for participation in the project. This strategy built on existing staff and allowed the program to be offered in rural areas where it was anticipated that master's-level trained practitioners would be difficult to recruit.

A second change was the adoption of a condensed version of the intervention in the fall of 2012. Developed by the University of Washington in response to discussions with grant partners about program costs and sustainability, the revised protocol included all the core content of the original intervention, but reduced the number of home visits to four (rather than eight), supplemented by two additional phone calls, as follows: weeks 1 and 2—home visit, week 3—phone call check-in, week 4—home visit, week 5—phone call check-in, week 6—home visit, and four monthly follow-up phone calls.

One of the primary objectives of the project was to develop partnerships to translate and sustain the STAR-C program in both a rural and an urban area of Oregon. To achieve this objective, the Oregon Department of Human Services, Seniors and People with Disabilities Division, partnered with two Area Agencies on Aging (AAAs) (Multnomah Aging & Disability Services and Rogue Valley Council of Governments Senior & Disability Services) and the Oregon Chapter of the Alzheimer's Association to implement STAR-C in three counties.

The goal of the grant was to provide the STAR-C intervention to at least 168 family caregiver/care receiver dyads. The target population was primary caregivers of persons experiencing dementia, where the caregiver reports difficult mood and behavioral challenges.

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[1] Logsdon, R. G., McCurry, S. M., & Teri, L. (2005). STAR-Caregivers: A community-based approach for teaching family caregivers to use behavioral strategies to reduce affective disturbances in persons with dementia. *Alzheimer's Care Quarterly*, 6, 146–153.

The Oregon translation's eligibility screening form eliminated the requirement that an individual have a doctor's diagnosis of Alzheimer's disease to remove potential barriers to participation for families that had not yet gotten a diagnosis. Instead, Oregon added a question asking if the dementia had lasted at least 6 months, and asked caregivers to provide the diagnosis if known.

Key criteria in participant selection included the following: (1) person with dementia had experienced at least three behavioral issues from a provided list over the past 2 weeks; (2) person with dementia did not have a history of drug/alcohol abuse within the past year and had not been hospitalized for mental illness in the past year; (3) caregiver lives at home with the person with dementia, spends at least 4 hours a day with him or her, and is willing to participate in the program; (4) caregiver does not expect to move or place the person with dementia into a long-term care facility within the next 6 months.

The participating AAAs' regional coordinators were responsible for enrolling participants. They engaged in active outreach through community presentations and distribution of promotional materials. Specific strategies included newspaper articles that featured participants discussing the impact of the program on their lives; presentations and information shared with medical providers, elder law attorneys, adult day and other dementia care programs; and information distributed through libraries, parish nurses and other faith-based organizations, and senior meal sites. In addition, Alzheimer's Association staff contacted potential individuals in the two target regions who had called the National Helpline to ask about the STAR-C program and reviewed existing case-managed clients to identify potential participants. Some of the issues that affected recruitment included the following:

- Caregivers who did not meet the enrollment criteria; these individuals were referred to other AAA services, including Powerful Tools for Caregiving workshops, case management, or Family Caregiver support services.

- Some eligible caregivers were reluctant to commit to a multisession program in their homes and declined to participate. The Multnomah regional coordinator reported anecdotally that switching to the slightly shorter condensed version of STAR-C was helpful in recruiting some of the caregivers who were concerned about the time commitment. In some cases, consultants arranged to meet with caregivers in locations other than their homes if the caregiver preferred.

- A number of potential participants never started the program or were unable to complete because the care recipient died or was placed in long-term care facilities or the caregiver's health deteriorated to the point where he or she was unable to participate.

Ultimately, Oregon recruited 255 participant dyads (persons with dementia and their caregiver), of which 189 enrolled and 156 completed the intervention.[2] Sociodemographic characteristics of the enrolled participants are summarized in ***Table B-10***. The majority of persons with dementia were over 60 years of age while 25%t of caregivers were under 60. Persons with dementia were evenly split between female and male, while 75% of caregivers were female.

Table B-10
Sociodemographic Characteristics of Participants in Oregon's STAR-C Project

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Total	189		189		378	
Age						
Under 60	3	2%	41	25%	44	13%
60+	166	98%	126	75%	292	87%
Age Missing	20	—	22	—	42	—
Gender						
Female	87	49%	142	75%	229	63%
Male	90	51%	47	25%	137	37%
Gender Missing	12		0		12	
Geographic Location						
Urban	104	55%	104	55%	208	55%
Rural	85	45%	85	45%	170	45%
Geographic Location Missing	0	—	0	—	0	—
Relationship						
Spouse	113	64%	113	64%	226	64%
Unmarried Partner	2	1%	2	1%	4	1%
Child	0	%	56	32%	56	16%
Parent	56	32%	0	%	56	16%
Other Relative	1	1%	2	1%	3	1%

(continued)

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[2] STAR-C in its original format included eight weekly home visits that deliver the key content and skill-building components of the intervention, followed by four monthly phone calls to support maintenance. Oregon made the decision to consider "completers" those who had completed the full home-visit portion of the intervention and completed the post-treatment survey/assessment. In the condensed 6-week protocol with four home visits and two phone calls, followed by the same four monthly phone calls to support maintenance, Oregon continued to consider "completers" those who had completed the core 6-week visit/phone call delivery of the intervention.

Table B-10 (continued)
Sociodemographic Characteristics of Participants in Oregon's STAR-C Project

Sociodemographic Characteristics	People with Dementia, #	People with Dementia, %	Care-givers, #	Care-givers, %	Total, #	Total, %
Non-relative	4	2%	4	2%	8	2%
Relationship Missing	13	—	12	—	25	—
Ethnicity						
Hispanic or Latino	51	41%	51	30%	102	35%
Not Hispanic or Latino	72	59%	120	70%	192	65%
Ethnicity Missing	66	—	18	—	84	—
Race						
White—Non-Hispanic	65	53%	111	65%	176	60%
White—Hispanic	50	41%	48	28%	98	33%
American Indian or Alaska Native	2	2%	3	2%	5	2%
Asian	0	0%	0	0%	0	0%
Black or African American	4	3%	4	2%	8	3%
Native Hawaiian or Other Pacific Islander	0	0%	1	1%	1	0%
Persons Reporting Some Other Race	2	0%	5	3%	7	2%
Persons Reporting 2 or More Races	0	0%	0	0%	0	0%
Race Missing	66	—	17	—	83	—
Veteran Status						
Veteran	20	50%	7	18%	27	34%
Non-Veteran	20	50%	32	82%	52	66%
Veteran Status Missing	149	—	150	—	299	—

— = Not applicable.

A major implementation challenge was cases where the consultant was not able to meet with the caregiver alone, so STAR-C was conducted with both the caregiver and care-receiver present. There seemed to be a combination of reasons this occurred: lack of caregiver willingness to accept use of respite, caregiver preference to have the care recipient present, consultants not fully appreciating the need for private sessions, and perhaps regional differences (this seemed to happen more in the urban implementation site). The University of Washington staff emphasized this issue in training new consultants and encouraged the regional coordinators to talk with potential participants about the issue when recruiting caregivers for the program, but it continued to be a challenge in some of the interventions.

Outcomes of Intervention Program

The anticipated outcomes proposed for this project were (1) a decrease in frequency and severity of behavior challenges among care recipients, (2) a decrease in depression and caregiver burden among caregivers, and (3) successful translation of the STAR-C program as a community-level intervention in both an urban and rural setting with fidelity to the core elements of the original research.

To assess the impact of the program on caregiver outcomes, participants were asked to complete and mail in a pre-assessment packet prior to starting the program. They were then asked to complete identical assessments immediately after completing the eight home visits, and again after completing the four monthly calls (approximately 6 months after initiating the program). The assessment included the following components:

- Screen for Caregiver Burden (SCB)—25 questions
- Center for Epidemiologic Studies—Depression (CESD)—20 questions
- Revised Memory & Behavior Problem Checklist (RMBPC)—24 questions
- Quality of Life-AD Proxy (QoL-AD)—13 questions
- Intent to institutionalize—2 questions (these were additional to original assessment)

Oregon chose to rely on mailed consent and assessment forms rather than having staff meet with participants to collect these data. This was done to eliminate the cost and staff time of an additional face-to-face home visit. Of 189 patients who began the program, 174 completed and returned the baseline assessment survey, 106 completed the post-treatment survey, and 54 completed the 6-month survey.

To analyze the impact of the program on the measures listed, except for the intent to institutionalize, baseline characteristics of caregivers and care receivers were summarized using proportions or means and standard deviations, as appropriate. The evaluators conducted within-subject comparisons using change in the outcomes at baseline and post-test, and compared change scores from baseline to post-test using paired *t tests* for participants with data at both time points. In longitudinal analyses, the evaluators used both post-treatment visits (2 and 6 months) and time, controlling for baseline value of the outcome, using generalized estimating equations with a normal link function and robust standard errors and an exchangeable correlation structure. This method allows for the inclusion of all available participant data (rather than dropping cases in which there were any missing data points).

Oregon employed most of the assessment forms used by the University of Washington in the original STAR-C research. Although helpful in assessing translation of the program, it meant considerable paperwork for participants. Some participants simply declined to fill out the surveys or indicated that they were too overwhelmed and unable/unwilling to complete the additional forms. Also, Oregon used an adapted version of the RMBPC that employed a yes/no format rather than a scale for the rating of behavior occurrence. The change in the RMBPC made comparisons between the original findings and Oregon's translation difficult for this section of the assessment.

The analysis indicated significant post-intervention reductions in caregiver depression, burden, and reactivity to care-receiver behavior problems, and significant post-intervention reductions in care-receiver depression. At the 6-month longitudinal follow-up, significant reductions in caregiver reactivity to behavior problems and significant reductions in care-receiver depression were maintained. Caregiver depression and burden were still lower than at the baseline assessment, although no longer at a statistically significant level.[3] Caregivers also reported significant improvements in care-receiver quality of life.

A brief satisfaction survey was developed in the third year of the project. The survey was mailed to all participants who had completed the intervention at that point with a stamped return envelope, and surveys were sent to participants as they completed the program during the rest of the project. Survey questions asked about participants' perceived value of the program and skills they gained, and asked about willingness to have paid for the program.

Participants generally reported high levels of satisfaction and appreciation for the program. Also, case managers who were trained to serve as STAR-C consultants were very positive about being able to offer the program to caregivers, being appreciative of this additional set of skills they could offer to families, and reporting anecdotally on the changes they observed in participating caregivers.

Infrastructure Development

The program was successfully translated in both urban and rural settings with fidelity to the core elements of the original research. Staff were initially recruited from among existing case managers at the two participating AAAs. Initial training for the regional coordinators and STAR-C consultants was provided by three staff persons from the University of Washington. The 2-day training covered the basics of program implementation, and also included an additional half day with the Multnomah AAA program evaluator to talk through logistics of how various forms and data would be collected at each site. In the second year, the training was shortened to 1½ days, and was led by the two trained regional coordinators from the AAAs, with guidance and participation from the three University of Washington staff. STAR-C consultants from the first year also attended this training, which provided them with a refresher course and allowed them to share examples and role-play situations for the new consultants. By the end of the grant, trained STAR-C consultants included the two AAA's regional coordinators, nine AAA case managers, and two private geriatric care managers.

In addition to training new consultants, the two regional coordinators were critical to implementation in each AAA. Key roles included (1) outreach and recruitment; (2) screening of potential participants, oversight of consent and assessment forms, and assignment of eligible participants to available STAR-C consultants; (3) coordination of the STAR-C consultants,

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[3] This was possibly because of the reduced number of follow-up surveys available for analysis at 6 months. Also, it should be noted that caregivers in the Oregon program were initially more depressed and had higher burden levels than those in the original randomized trial.

including scheduling, assistance, and addressing any challenges that consultants encountered; and (4) participation in monthly grant coordination calls.

The early development and use of a shared web-based tracking tool was very helpful in allowing the grant partners to share and track information on each participant's progress through the intervention. The tracking tool was only available to those with approved access and included each participant's assigned identification number (to protect identities). The tool was initially established on a state-based system (GovSpace) and eventually moved over to a Google document.

Sustainability

Program sustainability was part of monthly coordination call discussions and both AAAs actively explored a variety of options for keeping the program going beyond the end of the grant. Activities taken to address sustainability included the following:

- Developed cost analysis data to make the case for coverage through health insurance plans.
- Worked with University of Washington to develop the condensed version of the intervention to reduce the cost of the program.
- Included a question about participants' willingness to pay for the program as part of the satisfaction survey.
- Trained private geriatric care managers who expressed interest in being able to provide the program independently on a fee-for-service basis once the grant ended.
- Recruited a volunteer retired business consultant to develop a business plan to sustain STAR-C.
- Proposed coverage of the STAR-C program for Medicaid clients to newly developed coordinated care organizations.

As the grant ended in June 30, 2013, both AAAs were working to continue offering the intervention through a combination of Older American Act Family Caregiver support program funding and funding through healthcare organizations. There were no plans for additional Oregon AAAs to adopt the STAR-C program because the overall costs and demands on staff time were a challenge, given limited budgets.

Recommendations From the Project Implementation Team for Future Efforts

Translation of an evidence-based program is complicated and time-consuming. Oregon learned and benefited from the translation process, but is now aware of the work and time involved in being an early adopter of an evidence-based program. In particular, cost analysis is not routinely done for programs and services offered by AAAs. More models for tracking and analyzing programs—including translational projects with considerable startup costs, and community-based projects where there are high recruitment and outreach costs with potentially high rates of discontinuation because of the length of the program—would greatly help local organizations and states working to analyze costs.

Outreach and recruitment are critical to program success, and were a greater challenge than anticipated—both implementation sites wished that they had used paid advertisement more actively from the beginning of the program. Also, the choice of STAR-C consultants is important to the success and effectiveness of the program. Oregon selected this program based on the ability to use existing case managers to offer it. However, the regional coordinators recognized quickly that it was important to choose consultants who are able to step out of their traditional case management roles, are flexible, and are able to empower participants.

Developing provider trust is also critical; perhaps because of lack of familiarity with the program or uncertainty about how long it would be available, providers were slow to refer participants initially. Both implementation sites conducted outreach to providers, with Multnomah offering several provider education events. Although these efforts took time and added work for the coordinators, they were important in developing understanding and trust to encourage referrals.

During this project, better defining the Alzheimer's Association's role would have been helpful. The Alzheimer's Association Chapter in Oregon has limited direct program staff and went through several staff transitions during the course of this project. Although the chapter was supportive of the project, its role (by choice) was limited to support for the project advisory group and help with training as needed. Developing a stronger role for the chapter in terms of regular referrals and more active involvement with the program may have helped with outreach and program credibility among providers, and helped build more ongoing partnerships between the implementing AAAs and the chapter.