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Translating Evidence-Based Dementia Interventions to the Community: Experience of the Administration on Aging's ADSSP Grantees

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Executive Summary

A large, growing number of Americans are living with dementia. These individuals and their family caregivers face great difficulties in coping with and managing the condition. At present, there are no biomedical treatments that can prevent or cure dementia or even delay its onset and progression. Numerous nonpharmacological interventions have been shown in rigorous studies to reduce the negative effects of dementia on both people with the condition and their families. Unfortunately, these evidence-based interventions are not available to the vast majority of communities across the country.

In 2008, the Administration on Aging (AoA) shifted the focus of the Alzheimer's Disease Supportive Services Program (ADSSP)—AOA's program that provides grants to states for projects to improve services to people with dementia and their caregivers—to support projects that translate evidence-based, nonpharmacological interventions from research to practice in the community. Sixteen states used ADSSP grants to conduct translation projects to implement nine existing evidence-based interventions. These projects are now complete. This report analyzes the experience of those ADSSP state grantees and their community partners to understand what issues they confronted and the strategies they used to address them.

Methods

To obtain information about issues related to the translation process, the National Alzheimer's and Dementia Resource Center (NADRC) team conducted focus groups and interviews with selected grantees and community partners. To obtain additional information, the NADRC team also reviewed published articles about the ADSSP translation projects and grantee translation reports submitted to AoA.

Findings

Organizations translating evidence-based interventions to community settings had to successfully address eight main issues:

1. Selecting an intervention among the many available options
2. Working with community partners
3. Recruiting and retaining program participants, some of whom may be interested in only some part of the intervention or may not have time for the entire intervention

4. Hiring, training, and retaining staff who are willing and capable of delivering the intervention in a standard way at the community level
5. Monitoring for fidelity to the “core” of the original intervention to obtain the positive impacts of the original academic studies
6. Making modifications to the original intervention, most commonly by reducing the length of the intervention, targeting new populations, and reducing data collection
7. Evaluating the translated program to determine if results were comparable to the original intervention
8. Sustaining the translated program when demonstration funding ends

The ADSSP grantees and their community partners used a number of strategies to address the issues they faced. They described, for example, working directly with the original researcher to provide staff training and fidelity monitoring. Some respondents described choosing an intervention that could be delivered by existing community partner agency staff or one that could be delivered by telephone to reach people in rural communities who cannot get to the partner agencies. Strategies that grantees and community partners used to address difficulties in retaining trained staff included regular supervision, peer support, and opportunities for professional development.

The AoA-funded projects resulted in a large amount of practical information about how to translate existing evidence-based interventions—shown to benefit people with dementia and their family caregivers—into effective supportive service programs at the community level and ways to reduce problems that interfere with successful implementation. The translation projects developed new tools and materials to support implementation, including manuals, position descriptions, and training materials. The projects also developed new delivery methods that can help to reduce costs and increase the number of persons with dementia and family caregivers who can be identified and served. The information, tools, materials, and delivery methods developed through the AoA-funded projects will be useful to other organizations and agencies that are conducting or want to conduct such projects. Although some programs were able to sustain their translations, many faced difficulty finding ongoing funding streams that could provide a reliable source of financing over the long term.

INTRODUCTION

More than 5 million Americans are living with dementia, and the number of people with Alzheimer's disease, the most common cause of dementia, is projected to increase to 13.8 million by 2050 (Hebert et al., 2013; NIA, 2016). Dementia reduces a person's cognitive function, behavior, and ability to perform everyday activities such as shopping, paying bills, and managing medications (Alzheimer's Association, 2016; NIA, 2016). Over time, individuals require more assistance from others to meet basic needs, which adversely affects their quality of life. Many family caregivers of people with dementia experience negative physical, emotional, and financial effects associated with caregiving and are, on average, more likely to experience these negative effects and for longer periods of time than family caregivers of other older people (Alzheimer's Association, 2016; Kasper et al., 2015; National Academies of Sciences, Engineering and Medicine, 2016).

Currently, no pharmacological treatments exist that can prevent, cure, or delay the onset or progression of Alzheimer's disease or of most other diseases and conditions that cause dementia (Cummings et al., 2014; United States Department of Health and Human Services [HHS], 2016; NIA, 2016). Rigorous research has shown, however, that nonpharmacological interventions can have statistically significant positive effects for people with dementia and their family caregivers (Gitlin et al., 2015; National Academies of Sciences, Engineering and Medicine, 2016). These interventions include caregiver training and education, caregiver counseling and support groups, person with dementia exercise and activity programs, and strategies to address sleep disturbances and difficulty in bathing.

Positive effects that have been found for the nonpharmacological interventions used in the translation projects discussed in this report include the following:

- **Positive outcomes for people with dementia:** Reduced self-reported depression, shame about memory problems, and difficulty coping (Bass et al., 2014; Clark et al., 2004; Teri et al., 2003); increased independent functioning (Gitlin et al., 2001); reduced self-reported unmet needs (Bass et al., 2014); reduced behavioral symptoms (Gitlin et al., 2005, 2008; Teri et al., 2005); and delayed nursing home placement (Gaugler et al; 2013; Mittelman et al., 2006).

- **Positive effects for family caregivers:** Reduced caregiver burden, stress, depression, and anxiety (Bass et al., 2013; Belle et al., 2006; Hepburn et al., 2005; Schulz et al., 2002; Ostwald et al., 1999; Teri et al., 2005); increased quality of life and well-being (Belle et al., 2006; Mittelman et al., 1996, 2006); reduced negative caregiver reactions to behavioral symptoms (Gaugler et al., 2016; Gitlin et al., 2009; Mittelman et al., 2006; Ostwald et al., 1999; Teri, 2005); and increased use of adaptive coping strategies, caregiving skills, confidence, and adaptive coping strategies (Gallagher-Thompson et al., 2003; Gitlin et al., 2008; Hepburn et al., 2005; Ostwald et al., 1999).

Not all people with dementia and family caregivers benefit from nonpharmacological interventions, and the amount of benefit varies. Nevertheless, the positive effects described above indicate that available interventions can help people with dementia and their family caregivers, even though pharmacological treatments are not yet available. Unfortunately, the nonpharmacological interventions that have been shown to have positive effects are not generally available in communities across the country (Gitlin et al., 2015; Maslow, 2012; National Academies of Sciences, Engineering and Medicine, 2016).

In 2008, the Administration on Aging (AoA) redesigned its Alzheimer's Disease Demonstration Grants to States program, renaming it the Alzheimer's Disease Supportive Services Program (ADSSP) and changing its primary focus for the next several years to supporting the translation of evidence-based nonpharmacological interventions from research to practice in community settings. From 2008 to 2010, AoA provided ADSSP grants to 16 states to demonstrate how existing, evidence-based interventions can be translated into effective supportive service programs at the community level.

AoA developed specific criteria for an intervention to be considered evidence based (HHS, 2008, 2009, 2010). Specifically, an evidence-based intervention had to be

- tested in a randomized controlled trial (RCT), the gold standard for rigorous research, with results published in a peer-reviewed journal;
- effective at improving, maintaining, or slowing the decline in the health or functional status of older people with dementia or their family caregivers;

- suitable for deployment through community-based human services organizations and delivery by nonclinical workers or volunteers; and
- translated into practice and ready for distribution through community-based human services organizations.

AoA also funded the National Alzheimer’s and Dementia Resource Center (NADRC) to provide technical assistance for the state grantees and their community partners who were conducting the translation projects.

Table 1 shows the nine evidence-based interventions that ADSSP state grantees selected for translation. Georgia conducted projects to translate three evidence-based interventions. Additional details and references for the evidence-based interventions are provided in *Appendix A*.

Table 1. Evidence-Based Interventions Selected for Translation by States With ADSSP Grant Funding Initiated Between 2008 and 2010

Evidence-Based Intervention	States That Selected the Intervention	Description of Intervention
BRI Care Consultation™	Georgia Tennessee	A telephone-based intervention aimed at assisting people with dementia and their family caregivers. Trained care consultants follow a telephone contact protocol to perform an ongoing assessment aimed at collaboratively identifying specific concerns for the person with dementia or the family caregiver. Action steps are then developed to achieve certain goals with periodic progress evaluation. The care consultant initiates phone contacts to evaluate progress at regular intervals with a minimum of 10 contacts in the first year.
Coping with Caregiving	Arizona Nevada	Group workshops are provided to family caregivers at weekly 2-hour sessions over 10 weeks; topics include stress management, behavior problem management, communication skills, mood management strategies, and basic education about dementia and caregiving.
New York University Caregiver Intervention (NYUCI)	California Florida Georgia Minnesota Utah Wisconsin	Six counseling sessions occur over a period of 4–6 months and address specific challenges that a primary caregiver or family is encountering. The program consists of four components: individual counseling sessions with the primary caregiver, family counseling sessions, encouragement to attend weekly support group sessions, and ongoing ad hoc contact with the counselor to provide additional information and support.

(continued)

Table 1. Evidence-Based Interventions Selected for Translation by States With ADSSP Grant Funding Initiated Between 2008 and 2010 (continued)

Evidence-Based Intervention	States That Selected the Intervention	Description of Intervention
Reducing Disability in Alzheimer's Disease (RDAD)	Ohio	Training takes place in the home over 12 one-hour sessions and includes the person with dementia and the caregiver as active participants. The person with dementia is guided through a series of exercises while the caregiver observes. The caregiver is also provided with dementia education and instructed in behavior management through problem-solving.
Resources for Enhancing Alzheimer's Caregiver Health (REACH II)	Georgia North Carolina	Caregiver training and counseling are provided over a 6-month period in nine 1.5-hour sessions in the person's home, three half-hour telephone calls, and five telephone support group sessions. The intervention focuses on five areas linked to caregiver stress: safety, self-care, social support, emotional well-being, and problem behaviors. A risk appraisal is used to determine the areas that need the most attention.
Savvy Caregiver	California Maine Michigan	Group workshops are provided to family caregivers at weekly 2-hour sessions over 6 weeks. Session content is designed to train family caregivers in the basic knowledge, skills, and attitudes needed to handle the challenges of caring for a family member with dementia and to be an effective caregiver.
Skills2Care™	New Jersey	An environmental intervention can include up to eight in-home sessions and one 30-minute phone session over 6 months. It is designed to help family caregivers modify their living space to be a more supportive environment, so the person with dementia will exhibit fewer behavioral symptoms and experience a slower rate of decline.
STAR-Community Consultants (STAR-C)	Oregon	A behavioral intervention delivered over 6 months in the home once a week for 8 weeks. Treatment components include general education about Alzheimer's disease, practice using the Antecedent-Behavior-Consequence model to reduce behavior problems in dementia, communication skills, relationship between mood and pleasant events, and caregiver support.
Tailored Activity Program (TAP)	Kentucky	Six 90-minute home visits and two brief telephone contacts over 4 months by occupational therapists to provide caregivers techniques to identify the person's existing abilities and previous interests. The contacts help devise activities that build on those abilities and interests as a way to reduce behavioral disturbances and depression in the person with dementia.

ADSSP = Alzheimer's Disease Supportive Services Program.

The translation projects shown in Table 1 are now complete. This report focuses on the translation experience of the state grantees and their community partners, the challenges they faced, the strategies they used to address those challenges, and the outcomes they achieved in their ADSSP-funded translation projects. Additional information about the ADSSP translation projects is available in published articles and translation reports listed in the *References*.

In addition to AoA funding through ADSSP grants to states, the U.S. Department of Veterans Affairs (VA), the Rosalynn Carter Institute for Caregiving, and other government and private sector agencies and foundations have funded projects to translate some of the same and other evidence-based, nonpharmacological interventions to help people with dementia and their family caregivers (Maslow, 2012). This report does not address the experience of the agencies and individuals that conducted these other translation projects.

Findings from this report will be helpful to organizations and agencies that are conducting or want to conduct evidence-based nonpharmacological interventions for people with dementia and their family caregivers. Conclusions about the translation process also will be helpful to government and private sector agencies and foundations that are or could be funding such translation projects.

REVIEW OF GENERAL TRANSLATION LITERATURE ON DEMENTIA CARE AND HEALTH-RELATED AND COMMUNITY CARE INTERVENTIONS

The published literature on translation of evidence-based interventions from research to practice ranges from biomedical treatments to interventions for community and residential care for people with various diseases, including dementia. The RTI International team reviewed 15 published articles and reports, including 3 articles specifically about issues and challenges in translation of evidence-based interventions for people with dementia and their family caregivers (Gitlin & Hodgson, 2015; Gitlin et al., 2015; Nichols et al., 2014). The other 12 articles and reports focus on issues in translation of evidence-based interventions in more general health care, health-related, and community care (Bass & Judge, 2010; Bertram et al., 2013; Horner & Blitz, 2014; Prohaska & Etkin, 2010; Woolf, 2008) and in health promotion and chronic disease management (Frank et al., 2008; Glasgow et al., 2003; Krist et al., 2012); hospital and other medical care (Bradley et al., 2004; Westfall et al., 2007); elder abuse (Teaster, 2011); and mental health care for older people (Scheinholtz, 2010).

Despite differences in focus, these articles and reports identify many of the same issues and challenges in translation of evidence-based, nonpharmacological interventions. All of the articles and reports strongly and uniformly emphasize the importance of translation studies of interventions that have been found to be effective in RCTs. The publications point out that many RCTs are conducted in academic research settings and, consequently, the tested interventions are usually implemented by specifically trained research interventionists. The interventionists follow a highly structured research protocol to deliver the intervention to research subjects who meet preset eligibility criteria that may identify a narrowly defined, homogenous sample.

Each of these factors—the academic research setting, the specifically trained interventionists, the highly structured research protocol, and a research sample that meets narrowly defined eligibility criteria—is unlikely to be replicated when the intervention is delivered in a community setting. Translation studies are essential to address and resolve issues and challenges that arise because of the mismatch between usual RCT procedures and effective procedures for implementation in community settings. Resolution of these issues and challenges is necessary to ensure that evidence-based interventions reach the people they are intended to help.

Other points made in most of the articles and reports are that government and private sector funding for translation studies is insufficient, and translation of evidence-based interventions from research to practice is complex. This is generally attributed to several factors that influence “contextual fit,” defined in one report as “the match between the strategies, procedures, or elements of an intervention and the values, needs, skills, and resources available in a setting” (Horner & Blitz, 2014). The articles and reports describe these contextual factors from various perspectives and use different terms, but most address the following factors:

- **General availability of resources in the community(ies) targeted for the translation project:** General provider expertise and resources for recruitment; sufficient and appropriate settings for the translated program; information and delivery systems (Bass & Judge, 2010; Bertram et al., 2013; Glasgow et al., 2003; Krist et al., 2012; Prohaska & Etkin, 2010); and ability and willingness to allocate these resources for the translation project (Horner & Blitz, 2014).
- **Characteristics of the lead agency for the translation project:** Ability to provide organizational support, including leadership from agency administrators, motivation and buy-

in from all levels of staff, and one or more internal champions for the project (Bass & Judge, 2010; Bertram et al., 2013; Bradley et al., 2004; Horner & Blitz, 2014; Nichols et al., 2014).

- **Characteristics of the intervention:** Fit with the mission of the lead agency, the agency's other programs, and the way the agency delivers services (Nichols et al., 2014; Prohaska & Etkin, 2010); research-based evidence of efficacy for the target population (Bass & Judge, 2010); well-defined procedures that describe what is to be done by whom, when, and why (Bass & Judge, 2010; Horner & Blitz, 2014; Nichols et al., 2014; Prohaska & Etkin, 2010); and implementation requirements that are not too difficult, time-consuming, or costly for the agency to provide (Bass & Judge, 2010).
- **Characteristics of the target population:** A sufficient number of potential participants in the target community(ies) who need, and are likely to want, the outcomes the translated program provides (Bertram et al., 2013; Scheinholtz, 2010) and whose culture, values, and preferences make them likely to use the program (Bass & Judge, 2010; Horner & Blitz, 2014).
- **Availability of trained staff to deliver the program:** Sufficient staff at the lead agency and partnering community agencies (if any) who have expertise to implement the translated program in the targeted community(ies) (Bass & Judge, 2010; Bertram et al., 2013; Horner & Blitz, 2014; Nichols et al., 2014; Teaster, 2011; Westfall et al., 2007) and whose culture and professional and personal values make them likely to accept and continue to deliver the program (Horner & Blitz, 2014).
- **Availability of staff training, supervision, and performance assessment:** Manuals and other training materials; qualified supervisory staff and adequate time for supervision; and tools and procedures for performance evaluation (Bass & Judge, 2010; Bertram et al., 2013; Horner & Blitz, 2014; Nichols et al., 2014; Teaster, 2011). One article proposes that training to deliver the specific program may be more important than any particular staff credentials (Bass & Judge, 2010).

The general translation articles and reports reviewed by the NADRC team emphasize the importance of maintaining fidelity to the original intervention to achieve similar outcomes (Bass & Judge, 2010; Frank et al., 2008; Gitlin, 2015; Prohaska & Etkin, 2010; Scheinholtz, 2010).

The articles and reports also acknowledge that modifications to the original intervention may be

needed to improve contextual fit and acceptance and use of the translated program (Bass & Judge, 2010; Bradley et al., 2004; Gitlin et al., 2015; Scheinholtz 2010). Balancing the need for changes with maintenance of essential components of the original intervention is a frequently stated goal (Gitlin et al., 2015; Horner & Blitz, 2014; Nichols et al., 2014).

Many of the translation articles and reports also emphasize the importance of evaluation and the need to select outcome measures that are meaningful to agency administrators and people who will or could use the translated program (Bass & Judge, 2010; Horner & Blitz, 2014; Prohaska & Etkin, 2010; Scheinholtz, 2010). Cost-effectiveness and value to the agency's clients are likely to be important to agency administrators; valuable outcomes to people with dementia and their family caregivers are likely to include increased ability to manage daily activities and reduced behavioral symptoms.

Another common theme is lack of sufficient funding to sustain evidence-based programs that have achieved positive outcomes in translation projects. Time-limited grants have been the primary source of funding for translation projects, and the projects often struggle to find other sources to support sustained implementation (Bass & Judge, 2010; Gitlin et al., 2015; Krist et al., 2012).

A final theme addressed in several of the articles and reports is the need to consider changes in research methodology to reduce the complexity and difficulty of translating evidence-based nonpharmacological interventions from research to practice. Suggested changes focus on reducing problems of contextual fit by increasing attention to contextual factors early in the research process, for example, by testing original interventions in clinical and community settings that represent the settings where the program will ultimately be delivered (Gitlin et al., 2015; Glasgow et al., 2003; Westfall et al., 2007; Woolf, 2008). Use of practice-based research networks and hybrid research designs that combine effectiveness testing and implementation are also suggested.

METHODOLOGY

To describe and analyze the translation experience of ADSSP grantees and their community partners, the NADRC team reviewed published articles and reports about the ADSSP translation projects and publicly available translation reports that grantees submitted to AoA. In addition,

the NADRC team conducted focus groups and interviews with the ADSSP grantees and their community partners to gain the perspectives of individuals responsible for translating the evidence-based interventions.

Based on its review of the 15 articles and reports, the NADRC team identified eight important issues and challenges that agencies, individuals, and funders are likely to confront:

1. Selecting an intervention
2. Working with community partners
3. Recruiting and retaining program participants
4. Hiring, training, and retaining staff to deliver the program at the community level
5. Monitoring for fidelity
6. Making modifications to the original intervention
7. Evaluating the translated program
8. Sustaining the translated program

Because ADSSP grants supported the translation projects discussed in this report, these eight issues and challenges do not include the lack of funding for translation projects, noted as a problem in most of the reviewed articles and reports.

The NADRC team also developed questions about each of the issues. The team then used the eight issues and the related questions to guide its review of published articles on ADSSP-funded translation projects and publicly available translation reports that grantees submitted to AoA. The issues, challenges, and questions also were used to structure discussion in the focus groups and interviews with ADSSP grantees and their community partners.

Review of Published Articles on ADSSP-Funded Translation Projects

To identify published articles on ADSSP-funded translation projects, the NADRC team conducted literature searches in the PubMed/Medline database for the following: names and abbreviations for the nine interventions tested by ADSSP grantees, known authors, and generic search terms and combinations of terms including Alzheimer's disease, caregivers, dementia, psychosocial education, dementia family caregiving, and translation.

The literature review identified 15 research articles pertaining to the ADSSP grant projects, including one article on BRI Care Consultation™, three on New York University Caregiver

Intervention (NYUCI), one on Resources for Enhancing Alzheimer’s Caregiver Health (REACH II), five on Savvy Caregiver, one on Skills2Care™, one on STAR-Community Consultants (STAR-C), two on Reducing Disability in Alzheimer’s Disease (RDAD), and one on both STAR-C and RDAD.

An additional 10 research articles were identified relating to the same interventions included in this report but discussing translation projects that were not funded with an ADSSP grant. These articles included three on REACH VA (an alternative version of REACH II), one on Savvy Caregiver, one on Skills2Care™, one on STAR-C, one on STAR-VA (an alternate version of STAR-C), and three on Tailored Activities Program (TAP).

Review of ADSSP Grantees’ Translation Reports

AoA required grantees that received ADSSP-funded translation grants to submit a “translation report” that detailed recommended procedures related to program implementation. Reports included recommendations on recruitment strategies, screening and enrollment procedures, training of interventionists, possible modifications to the intervention format or content, maintaining fidelity to core elements of the program, process and outcomes evaluation, and data collection and reporting strategies. These reports are intended to serve as guides for future translation projects and contain rich detail on the translation process.

Seventeen such translation reports were reviewed for this report: one on BRI Care Consultation™, two on Coping with Caregiving, four on NYUCI, one on RDAD, three on REACH II, three on Savvy Caregiver, one on Skills2Care™, one on STAR-C, and one on TAP.

Interviews and Focus Groups With ADSSP Grantees and Their Community Partners

The NADRC team conducted five focus groups and five interviews via telephone in April 2016. Focus groups included grantees and community partners where there was more than one grant project translating an evidence-based intervention. Focus groups were organized by intervention. For example, grantees and their partners that implemented the Savvy Caregiver intervention participated in the same focus group. Some interventions were implemented by only one grant project, and an interview was used in this situation.

Thirty people participated in these focus groups and interviews, representing a variety of roles within the grant projects, including original researchers of some interventions; state agency

on aging program directors; program staff at various translation sites, such as Area Agencies on Aging (AAAs) and Alzheimer’s Association chapters; and university researchers who assisted with training, data collection, and evaluation for some grants. **Table 2** lists the eight issues that were used to structure the focus groups and interviews. The questions were intended to elicit discussion about strategies the grantees and their partners used to address the identified issues and challenges.

Table 2. Issues in Translating Evidence-Based Nonpharmacological Interventions and Questions About Strategies to Address Them

Issues	Questions for Grantees and Community Partners About Strategies to Address the Issues
Selecting an intervention	What were the key factors in selecting this intervention? Did you consider other interventions, and if so, why did you decide not to use them?
Working with community partners	What experience did you have in working with partners in the implementation at the local level? What strategies worked well in helping partners prepare for and implement the program? Is there anything you would do differently?
Recruiting and retaining program participants	What strategies did you use for recruitment? Can you talk about what you learned through the process of outreach to rural participants or those from underserved racial or ethnic groups? For those sites that are still offering the program, can you talk about how the program is marketed now and what has been effective?
Hiring, training, and retaining staff to deliver the program at the community level	What was your experience in hiring, training, and retaining program staff delivering the intervention? How were the program staff identified or selected within each partner organization? Were there certain criteria used? Can you talk about your experiences of training and supporting program staff?
Monitoring for fidelity	How was fidelity to the original intervention monitored? What worked and what didn’t?
Making modifications to the original intervention	Did you make any modifications to the implementation at the community level? If so, what process did you use to ensure fidelity to the original intervention?
Evaluating the translated program	What aspects of evaluation/measures were retained from the original study? Did the translated program achieve similar outcomes to the original intervention?
Sustaining the translated program	Is this intervention being sustained after grant funding ends? What sustainability strategies would you recommend to other agencies or organizations looking to do similar work?

Source: ADSSP Evidence-Based Grant Translation Report.

TRANSLATION EXPERIENCE OF ADSSP GRANTEES AND THEIR COMMUNITY PARTNERS

Translating an evidence-based program is far more complicated and time-consuming than replicating an existing tested program. Each step of the process involved more time and effort—developing forms and procedures, going through Institutional Review Board review, training new staff with training systems that were still developing, and working through issues of program ownership and sustainability with the original researchers. As a result of the translation experience for each of the interventions, there is now a more established process for replication that will allow new organizations to adopt the program more easily.

Selecting an Intervention

ADSSP grantees and their community partners reported being interested in evidence-based programs for a few reasons. Many grantees and community partners reported wanting to offer services that would make a difference in the lives of their clients; implementing interventions that had demonstrated positive results in prior research studies was one way to maximize the likelihood that would occur. Some AAA community partners spoke about their experience with other evidence-based interventions—such as the Chronic Disease Self-Management Program and A Matter of Balance—that AAAs had incorporated as ongoing programs after grant funding ended. The community partners expressed their hope that AAAs would do the same with the dementia evidence-based intervention, assuming the translated program was found to be effective.

Once organizations decided to implement an evidence-based intervention in principle, they needed to choose among the nearly 100 interventions that have been shown to have some impact on caregivers or people with dementia. The original intervention researchers' geographic proximity or prior relationship with the grantee influenced the intervention choice in some instances, emphasizing the importance of personal connections and the availability of guidance by the intervention designer. Cost played a role in the choice of intervention for a number of grantees. For example, one grantee concluded that the lower cost of Coping with Caregiving would increase the likelihood that it could sustain the program after grant funding ended.

An important factor for a number of grantees was ensuring that the intervention they selected would address the specific needs of their desired target population. For example, grantees from

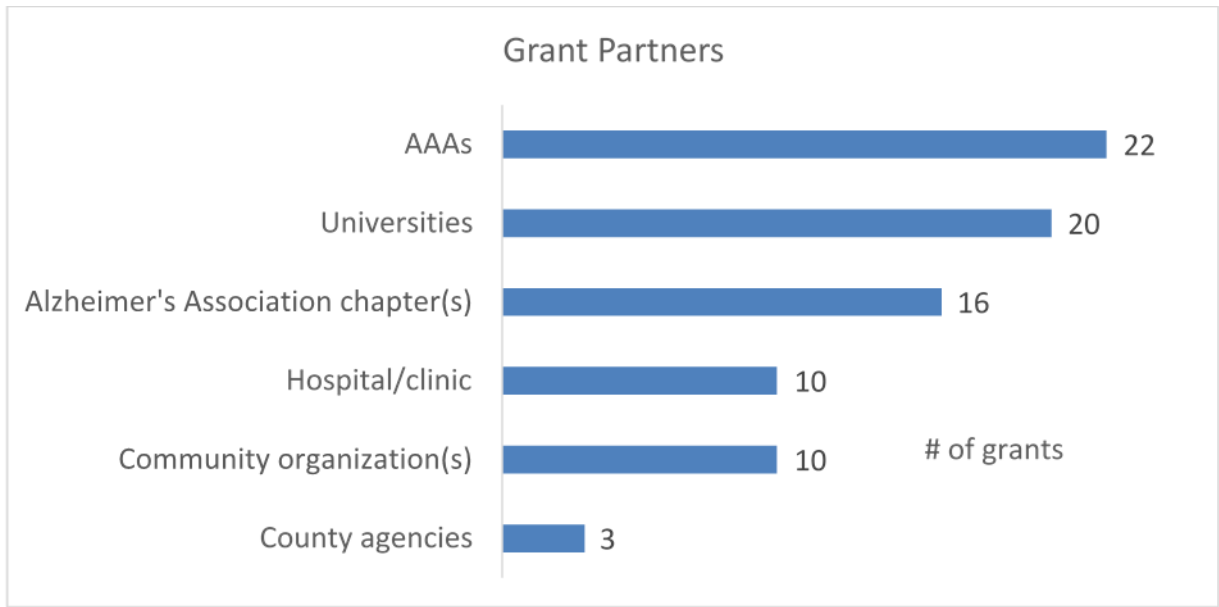
Georgia and North Carolina noted that one reason for choosing REACH II was that some program activities take place on the phone, which was helpful for serving people living in rural areas who have transportation difficulties. Similarly, the emphasis on phone and e-mail contact with BRI Care Consultation™ allowed the grantee to address the sponsoring organization's service waiting lists because it could serve more people than interventions requiring in-person visits (Easom & Holloway, 2015).

Some of the grantees also noted that it was important to choose an intervention that complemented existing programming or one where they could use their existing staff. Specifically, for the RDAD program, the caregiver education and behavioral trainings were well suited to complement the education and care consultation activities already being offered by the Alzheimer's Association chapters in Ohio. The RDAD program allowed the Alzheimer's Association chapters to expand beyond the usual one-time educational workshops and to offer more in-depth training to caregivers and people with dementia in their homes with 15 one-hour sessions (Teri et al., 2012).

Working With Community Partners

In most cases, grantees, which were state government agencies, worked with community agency partners at the local level to implement the program and deliver services. Grantees reported that their partners provided outreach and referrals to the program, delivered the intervention, and trained staff on how to deliver the intervention. AAAs were the most common partners and primarily provided outreach and referral and delivered the intervention. AAAs were followed in frequency by Alzheimer's Association chapters, hospitals and medical clinics, and other nonprofit community organizations (*Figure 1*). Most projects also partnered with university researchers to develop evaluation plans and collect and analyze program data. The original developer(s) of the intervention primarily provided the training of staff to deliver the intervention.

Figure 1. Types of Grantee Partners



Source: National Alzheimer’s and Dementia Resource Center analysis of grantee final reports.

Note: Grantees had the option of partnering with more than one type of organization.

The choice of partners is critical to any organization implementing a new program but is particularly important for evidence-based programs, because the partners must be willing to provide fidelity to the translated intervention and not implement the program as they think best. A number of grantees reported positive experiences with their collaborative partners throughout the course of their grant projects. Some had longstanding relationships with their partners so the collaboration seemed like a natural fit. For example, the Arizona and Nevada grantees had previously worked with the Alzheimer’s Association Desert Southwest Chapter and David Coon, PhD, a researcher who was one of the original developers of Coping with Caregiving.

Some grantees experienced challenges because of unanticipated changes at a partner organization or a partner organization’s inability to implement the intervention as intended. One grantee reported how a better assessment of the partner organization’s capacity to deliver the intervention would have avoided several problems. Grantees experienced some of the following challenges with partners:

- Failure to provide adequate staffing to deliver the intervention
- Insufficient understanding of the importance of fidelity to the intervention
- Lack of experience with data collection and reporting procedures

In one instance, a managed care organization, the primary partner for one of the grants implementing BRI Care Consultation™, was sold to another company soon after the grant was awarded, and the grantee spent much of the first year of the project determining how to obtain referrals from the new collaborative partner. Ultimately, the most effective method for identification and referral of participants was with the nurse case managers, who were able to secure permission and informed consent information from the patients with dementia and family caregivers for participation in the program.

Recruiting and Retaining Program Participants

Recruiting participants to Alzheimer's disease programs is often difficult for evidence-based programs because caregivers and persons with dementia need to commit to what is sometimes an extended intervention period and, depending on the organization, participate in an evaluation. To recruit participants for their evidence-based dementia programs, grantees primarily relied on the AAAs, Alzheimer's Association chapters, and other partner organizations for referrals (Coon, 2013a,b; Florida Department of Elder Affairs, 2013a; Hensley et al., 2012). The grant projects typically recruited potential participants by describing the program as a way to build skills in caregiving, not just education about the disease.

Recruitment methods differed across projects. Several grantees noted that recruitment through existing programs or by other organizations yielded the highest number of referrals to their translation programs compared to traditional methods of print media and participation at community presentations (Coon, 2013a,b; Easom et al., 2013; Hensley et al., 2012). Other grantees indicated that word of mouth by those who went through the intervention was the most successful recruitment method. Staff members who were most successful recruiting for the Minnesota grants implementing NYUCI seemed aware of the cultural preferences of caregivers in the target area, had established relationships with local providers, were able to identify potential referral sources, and promoted the program throughout the community (Paone, 2014).

The majority of grantees reported that recruitment for their evidence-based interventions was more time-consuming and challenging than with other programs. Barriers included potential participants not meeting the eligibility criteria for the program, caregivers' stoicism and unwillingness to receive help, and caregivers' concerns with the time commitment necessary to participate because the program had multiple sessions, or they felt overwhelmed by their

responsibilities (Oregon State Unit on Aging, 2013; Paone, 2012; Partners in Care Foundation, 2013). The California grant implementing the Savvy Caregiver intervention said that it was sometimes difficult to convey what the intervention entailed, especially with caregivers from ethnically diverse communities.

Hiring, Training, and Retaining Staff to Deliver the Program at the Community Level

Translation programs require technically capable staff, experienced with dementia, and willing to implement the intervention protocol and not rely solely on their own judgments. Not everyone is willing to strictly follow a protocol set by others. During interviews and focus groups, grantees spoke about the delicate balance of hiring professionals with the necessary credentials and experience who are also able and willing to follow the necessary rules for delivering the evidence-based intervention. Grantees highlighted the importance of adequate training and ongoing support to maintain fidelity to the intervention and of retaining interventionists over the course of the project.

Hiring

Many of the grantees used professionals from more varied disciplines than the original intervention. For example, the Ohio RDAD translation included nurses, counselors, and gerontologists in addition to the original disciplines of social work and physical therapy. Another intervention required occupational therapists as interventionists; the grantee had difficulty hiring occupational therapists and experimented with training activity directors and occupational therapy students. The occupational therapy students were not able to meet the project needs, which did not become clear until after the project started. Fortunately, the grantee was still able to achieve roughly the same outcomes as the original intervention.

In a few of the translations, role playing was used during the interview process to help determine the applicant's ability to deliver the intervention as intended. Role playing in the interview process for REACH II revealed that many candidates were able to provide information and referrals "but had less skill in shared problem solving, active listening, and teaching specific coping and stress management skills" (Alston et al., 2015). Most grantees interviewed noted that having interventionists experienced with Alzheimer's disease increased the chances of a successful implementation.

However, the type of prior experience with Alzheimer's disease and how it related to the particular intervention was also an important consideration in the hiring process. One of the grants implementing the Savvy Caregiver program learned that some trainers who had extensive experience leading dementia caregiver support groups struggled with the shift from sharing experiences with others to problem solving and skills training. Other grants reported using interventionists who had experience with evidence-based health promotion programs and were used to a structured and scripted curriculum, but were not always a good fit for the less structured, evidence-based dementia interventions.

Rather than hiring new employees, some grantees used existing staff from partner organizations to enhance sustainability, a practice that was fairly common with Alzheimer's Association chapters and AAAs. Some grantees contracted out for portions of the work. In one instance, a grantee implementing NYUCI found that contracting with licensed clinical mental health providers was better than hiring new employees because the hiring process "resulted in a lot of downtime and wasted money."

Training

Interventionists required training to deliver a program in the manner it was intended. In most cases, the original researcher who designed the intervention was involved in the training process, and sometimes in the first interventionists group meeting following training. In some of these translations, the original researcher also trained "master trainers" who then trained other interventionists.

For most interventions, the staff training was relatively short, which helped implementation. Among four interventions, the initial training was 2 days long (Alston et al., 2015; McCurry et al., 2015; Ohio Department of Aging, 2014; Wilson & Zsenak, 2012), but in a few instances, training was much lengthier. For example, one Savvy Caregiver grantee had a year-long training process involving classroom instruction, mentoring, and observation that culminated in certification (Michigan Office of Services to the Aging, 2014; Sherman & Steiner, 2016). The need to train some of the interventionists about Alzheimer's disease and dementia was also a common theme among grant projects using existing agency staff with limited direct experience with people who had dementia. In some cases, additional intervention trainings were for new

staff, but in other cases existing staff were identified as needing supplemental learning or a refresher.

Some programs used or developed online training, which allowed for less dependence on availability of the original researcher to provide training, enabled new staff to be trained later in the implementation when the original researcher might not be available, provided more flexibility with interventionist schedules, and allowed for a broader geographic reach. Online training also was less expensive, which addressed some grantee financial concerns. One drawback of online training was the lack of opportunity for asking questions, group discussion, or role playing, which were found to be important tools for effective trainings.

After training was completed, most programs used ongoing interventionist group meetings to provide supervision, problem-solve issues, and ask questions about the specifics of the intervention. Several grantees reported that staff training and supervision took a lot of time but consistently spoke about the importance of providing a “safe space” for staff to bring up questions and share experiences for a successful implementation.

Retention

Once they were trained and experienced, staff who delivered the program were valuable resources to the translation because they had the skills and knowledge to implement the evidence-based program. Ongoing training, supervision, opportunities for professional development, and the ability to interact with other interventionists were some of the factors that grantees identified for retaining trained staff. Two grantees noted in interviews that when staff could see the changes they were helping people make, they felt good about their role and were more committed to staying involved.

Two issues that led to loss of trained staff or poor morale were slow recruitment of program participants and burdens of other job responsibilities. One grantee noted in an interview that episodic provision of the program because of slow recruitment made it hard to retain the skills learned through training. If trained staff had too many other job responsibilities, they were not able to give adequate time and attention to the program and, therefore, were less engaged or committed. Finally, some trained staff became more attractive to other organizations because of their extensive training in an intervention and were hired away.

Monitoring for Fidelity

Fidelity to the original research protocol is important to obtain the outcomes found in the original studies. Although these projects were translations to community settings, an intervention provided in a different way might not achieve the outcomes realized in the original study. To help maintain fidelity, several grantees used the original researcher as a resource to monitor program activity. In addition to providing training on the intervention, some of these researchers provided training specifically on how to maintain intervention fidelity. As one grantee pointed out, it is important to explain to the operational staff the reasoning behind maintaining fidelity to the original program, why participants need to receive a certain number of sessions, or why a particular activity is important.

Maintaining fidelity was not always easy because the elements of the interventions are sometimes not well described in the research literature or depend on the clinical expertise of the intervention developer. Intervention manuals were an important tool to codify an intervention and maintain fidelity. When the NYUCI grant projects were funded, an intervention manual did not exist, so grantees from the various NYUCI project sites wrote one, with participation from the original researcher, so that the translation could be more standardized. For RDAD, the project staff developed a replication manual to accompany the original researcher's intervention manual that provided detailed protocols, data collection procedures, program flyers, screening forms, and letter templates to ensure consistent implementation statewide. Other interventions had extensive materials for grantees to use, including detailed manuals with referral forms, scripts to screen people for the program, and other important information to maintain fidelity to the original research. When there was no manual, consultation with the original research team helped maintain fidelity to the original intervention.

Another common tool to ensure fidelity was a checklist that covered the key components to be addressed in each session with caregivers or the person with dementia. One grantee kept a fidelity checklist for interventionists to use during intervention sessions. If participants drifted off topic, the interventionists could refer to the checklist to make sure they covered everything in the protocol. Other grantees used a checklist when listening to recorded sessions to identify any areas that may have been missed by the interventionist.

Many interventions made use of weekly, biweekly, or monthly conference calls to discuss fidelity issues and sometimes invited the original researcher to participate. One grantee said that while the interventionists were still learning, ongoing contact via conference calls helped solidify their commitment to fidelity. These meetings also allowed staff to discuss challenges and questions. Some grantees eventually moved to e-mail discussions once interventionists were comfortable and able to maintain fidelity with the program.

Other sources of monitoring fidelity included review of program evaluation forms completed by participants, role play and peer-to-peer learning, surprise visits to training sessions by program directors or master trainers, and recording intervention sessions. One grantee monitored fidelity by listening to recorded sessions and provided feedback to the interventionists.

Making Modifications to the Original Intervention

Although the translation projects sought to maintain fidelity to the original interventions, reflecting the shift from research to practice, some projects made modifications to accommodate real-world budget and resource constraints and to broaden the potential reach of the programs. In making these changes, project staff strove to address the needs of community partners and participants while attempting to maintain faithfulness to the core components of the intervention. Most of the changes related to the process of delivering the intervention, including the mode of program delivery and who delivered the intervention.

To maximize recruitment and to make services available to a broad segment of the community, many grantees relaxed participant eligibility requirements. For example, the original research on the Coping with Caregiving intervention examined impacts of the intervention on Latina and white women, while the translation projects expanded eligibility to all men and women of any race or ethnicity. Similarly, although the original NYUCI research delivered the intervention to only spousal caregivers, all but one of the translation projects expanded eligibility to include adult children (Alston et al., 2015). Other projects loosened requirements related to specific diagnoses: One project opted not to require participants to have a formal dementia diagnosis of Alzheimer's disease, while another broadened eligibility to include dementias other than Alzheimer's disease (Menne et al., 2014; Oregon State Unit on Aging, 2013; Primetica, 2013).

Translation projects also tested other ways of making interventions more accessible for participants. Skills2Care™ interventionists accommodated caregivers' needs by meeting via teleconference or Skype when an in-person meeting was impossible or by meeting outside of the home when the caregiver preferred to not have the person with dementia present. These exceptions were discussed case by case with the researcher to determine the best approach and how to maintain fidelity.

REACH II projects found that the number of sessions for the intervention was a concern for some caregivers and a barrier to participation. One REACH II grantee addressed caregiver reluctance to participate by providing respite care for the person with dementia (Florida Department of Elder Affairs, 2013b), while another recommended reducing the number of sessions in future projects.

Three other translation projects reduced the number of in-person sessions for various reasons such as travel time, harsh winter weather, and caregiver reluctance to participate because of other demands and responsibilities. Two grantees replaced group workshops with individual phone sessions to better address caregivers' unique situations and provide more one-on-one coaching (Coon, 2013a,b). Another project piloted a condensed version of its intervention in response to concerns about cost and sustainability, cutting the number of in-person sessions in half and adding two phone calls (Oregon State Unit on Aging, 2013).

Both budgetary constraints and practicality were factors in allowing a broader range of professionals to deliver interventions. The STAR-C researchers used master's-level mental health and health care practitioners to conduct the intervention, while the translation project used existing case managers at AAAs. Similarly, RDAD, which had been limited to social workers and physical therapists, was expanded to accommodate the range of backgrounds of Alzheimer's Association chapter clinical staff, including nurses, social workers, gerontologists, and counselors (Menne et al., 2014; Oregon State Unit on Aging, 2013). Both projects were able to demonstrate similar outcomes to the original research.

Evaluating the Translated Program

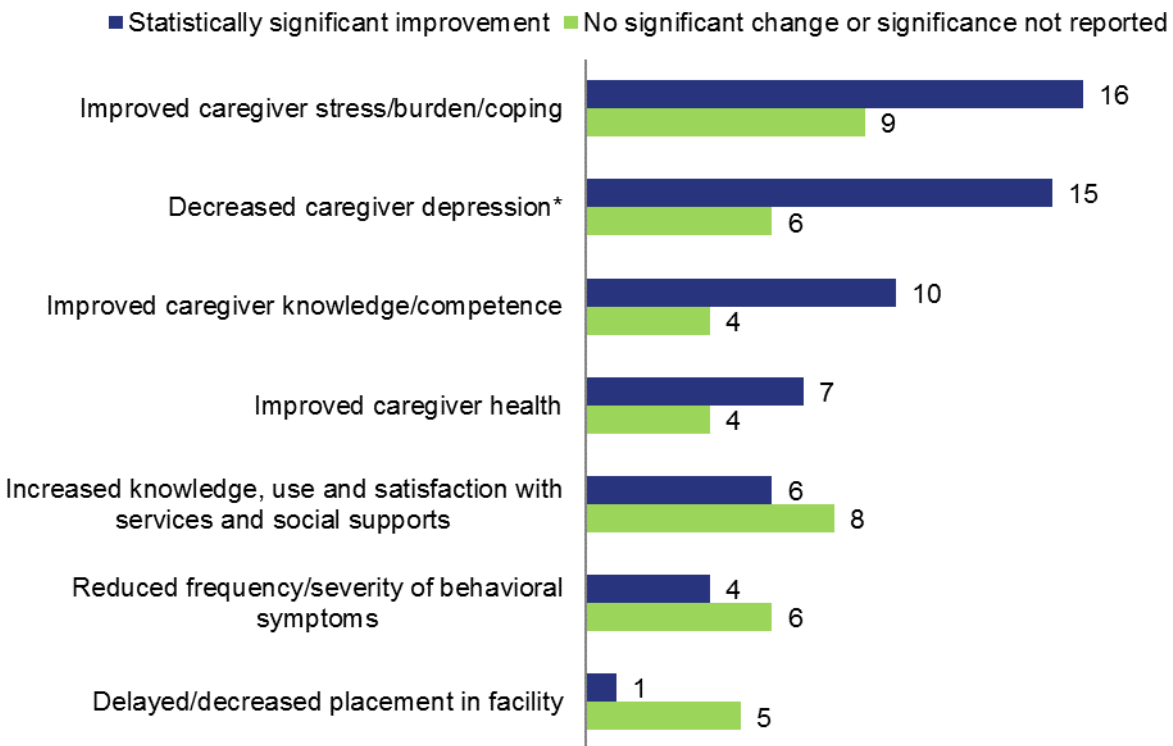
The interventions implemented in community settings through ADSSP grants were all tested through RCTs and shown to be effective in producing positive outcomes for some people with dementia and some family caregivers prior to the translation. To test whether the translations

yielded the same results, AoA required an evaluation of these grants. In translating these programs, grantees sought to demonstrate that similar outcomes could be achieved in “real-world” settings, but also had to develop evaluation plans that were sensitive to the limited resources of project staff and participants and the research skills of the grantee staff. ADSSP, by definition, funds services and is not a research program. Rather than using treatment and control groups as in the original RCTs, nearly all grantees used some form of pre-/post-testing, most often collecting data at baseline and immediately post-program and then conducting additional follow-up assessments at one or more subsequent periods, such as 3, 6, or 12 months post-completion of the intervention. Being able to show positive results of the translation helped projects obtain funding from other sources.

Grantees evaluated a variety of outcomes, with caregiver stress, burden, or coping abilities being the most common domains, followed by caregiver depression. Many grantees also examined changes in caregiver knowledge, competence, and use of community resources and social supports. Few grants measured outcomes for persons with dementia, with the exception of the frequency or severity of behavioral symptoms, which was tracked by nine grants. Six grants examined whether the intervention affected institutionalization rates. The number of grants reporting a statistically significant improvement on various outcomes is shown on **Figure 2**. The threshold for statistical significance was set at $p \leq .05$.

Most grantees used the same set of measures as the original researchers, with a few modest changes; however, many attempted to lessen the burden and costs of evaluation through modified data collection methods. As one researcher noted, when implementing evidence-based interventions in the community, “it is particularly important to ensure that the measures ... are clinically useful and meaningful to agencies, clinicians, caregivers, and persons with dementia” (Teri et al., 2012). Measures that meet this criterion will motivate staff to collect high-quality data.

Figure 2. Number of Grants Reporting Specific Outcomes



Source: National Alzheimer’s and Dementia Resource Center analysis of grantee final reports.

Note: The threshold for statistical significance was set at $p \leq .05$.

Some grantees simplified the data collection process by incorporating it into planned visits with participants. Whereas the original RDAD and NYUCI researchers used independent interviewers to conduct evaluation assessments, the translation projects staff collected the data during the in-person visits (Ohio Department of Aging, 2014). Other projects conducted assessments over the telephone or via mail, but the tradeoff with these approaches was sometimes low response rates. STAR-C mailed assessment forms to avoid the cost of an additional in-person visit, but found that, without staff calling to remind participants to return the forms, there were fewer responses at 6 months than in the original research. The Coping with Caregiving projects collected baseline and follow-up data over the phone, and even though assessment instruments were shorter than those used in the original research, response rates were lower. The grantee offered participants \$25 for each follow-up telephone interview completed, but even with the added financial incentive, response rates did not increase as much as expected (Coon, 2013a).

Despite simplifying data collection procedures, some grantees commented that the original assessment instruments themselves were too long and cumbersome for the participants and project staff to administer. Grantees reported that sometimes there were scales and other measures within the assessment instrument that were not central to the main outcomes. Many grantees modified the evaluation instruments either during or after the grant project. Both BRI Care Consultation™ and Coping with Caregiving grants moved to shorter assessment tools to streamline the evaluation process. Some Savvy Caregiver grants were also considering simplifying assessment measures going forward. Another project had to eliminate follow-up assessments altogether once grant funding was no longer available (McCurry et al., 2015).

Sustaining the Translated Program

The ADSSP program is a demonstration program; it is not meant to be an ongoing source of funding. The ADSSP evidence-based grants were funded for a 3-year demonstration period, and grantees had to consider permanent sources of funding for translation programs they wished to sustain. Grantees experienced varying degrees of success in maintaining their programs after the grant ended. Most programs continue to be delivered to some extent, although many have scaled back on the number of sites or on program components. The most obvious factor in successful sustainability is identifying sources of ongoing funding, but grantees also emphasized the importance of a proper fit between the agency and the specific intervention, staff buy-in, and early planning and expectations.

The most common source of continued funding cited was through Titles III-D (Disease Prevention and Health Promotion Services) or III-E (National Family Caregiver Support Program) of the Older Americans Act. Nearly one-third of grants have tapped these funds to provide continued support. Other sustaining funds have come from private foundations, the state, or the budget of the organizations delivering the program. A few programs, such as Savvy Caregiver and BRI Care Consultation™, are experimenting with offering services for a fee, but whether that approach will succeed is not yet known.

Organizational fit was identified as an important factor in sustainability. For example, the in-home service delivery aspect of RDAD was new to the Alzheimer's Association chapters implementing it; having chapter staff make home visits initially raised some safety and liability concerns. Ultimately the safety concerns were resolved for the grant project; however, the in-

home portion may be difficult to sustain because of organizational changes with the Alzheimer's Association. One of the NYUCI grantees faced challenges in sustaining the program because some of the delivery sites, including home care agencies and hospital-based programs, had no history of providing dementia caregiver support services. These organizations struggled to integrate a new focus into their programming (Paone, 2014). On the other hand, Savvy Caregiver was integrated successfully into the programming of community organizations and AAA partners in several grants. The enthusiasm of staff delivering the intervention was also cited as important to sustaining the program; they became strong advocates for the program after witnessing the positive impacts it had on clients.

Early planning for sustaining the project after the grant period and development of strong partnerships were other key factors mentioned by several grantees. In projects that were successful in sustaining the translation, the expectation that the partners would embed the intervention into their ongoing services was emphasized from the beginning by the grantee.

Ongoing discussions between researchers and project staff about how the program would be continued after the grant ended also contributed to establishing the logistical details of how the program would function. They considered issues such as who would conduct training after the grant, what kind of fidelity assurances the original researchers might want, and how to reduce the data collection burden once effectiveness in the community setting was demonstrated.

CONCLUSIONS

This report identifies key issues and challenges that organizations seeking to translate evidence-based interventions for people with dementia and their caregivers must address. To understand these issues and challenges and strategies to address them, the NADRC team drew from the experience of ADSSP grants funded by AoA in 2008, 2009, and 2010. The ADSSP grants were intended to demonstrate how existing effective RCT evidence-based interventions conducted by academics could be translated into effective community programs. Findings from these grants help provide guidance in moving from translating evidence-based dementia care interventions to sustained implementation in communities across the country.

In conducting their translation projects, the ADSSP grantees and their community partners identified many challenges and were generally able to develop strategies to overcome the

barriers. In their reports to the Administration for Community Living and during the focus groups and interviews, the grantees and their partners discussed these challenges and various strategies used to address them.

For example, many of the translation projects had difficulty retaining trained staff to deliver the translated programs. Grantees and their community partners used strategies such as regular supervision, peer support, and opportunities for professional development to address this challenge. In some instances, modifications were made to the original intervention to increase participation rates, address budgetary constraints, and engage other disciplines as interventionists. The modifications were generally successful, offering insights about translation and implementation that will be useful for other organizations that want to implement the same intervention. Most of the translation programs have been sustained to a greater or lesser extent after grant completion.

Awareness of the issues and challenges confronted by the ADSSP grantees and their community partners, and the strategies they developed to address those issues and challenges, will be useful to other organizations and individuals that want to make evidence-based interventions for people with dementia and their families available in communities across the country. Since 2011, AoA has funded grants intended to create dementia-capable home- and community-based service systems. The agency has required that grantees provide at least one evidence-based or evidence-informed intervention as part of the project, and many of the grantees are incorporating strategies developed in the ADSSP-funded translation projects discussed in this report.

Awareness of the issues, challenges, and strategies from the ADSSP-funded translation projects will also be useful to government and private sector agencies and foundations that are or could be funding such translation projects. Findings about the translation projects are also likely to spur ongoing discussions about methodological changes that could reduce the difficulty and time involved in moving from research to translation and practice for interventions that can benefit people with dementia and their family caregivers.

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Appendix A: Descriptions of Evidence-Based Interventions Translated by Alzheimer’s Disease Supportive Services Program Grants

A.1 BRI Care Consultation™/Cleveland Managed Care

SOURCE: Clark, P. A., Bass, D. M., Looman, W. J., McCarthy, C. A. & Eckert, S. (2004). Outcomes for patients with dementia from the Cleveland Alzheimer’s Managed Care Demonstration. *Journal of Aging & Mental Health*, 8(1), 40–51.

Bass, D. M., Clark, P. A., Looman, W. J., McCarthy, C. A., & Eckert, S. (2003). The Cleveland Alzheimer’s Managed Care Demonstration: Outcomes After 12 Months of Implementation. *The Gerontologist*, 43(1), 73–85.

PROGRAM OVERVIEW: BRI Care Consultation™ is a telephone-based intervention aimed at assisting people with dementia and their family caregivers. Care consultants, who are typically social workers or nurses, along with trained volunteers, run the intervention, which focuses on providing information about health problems, available informal supports and formal services, and emotional support. The care consultation also includes action steps that outline practical tasks to address problem areas.

TRAINING DESCRIPTION: This intervention is provided to in-home, local and long-distance caregivers and their care receivers with or without a formal diagnosis of Alzheimer’s or a related dementia. Care receivers living in the community or an assisted living facility, with or without a caregiver, are also able to participate. The trained care consultants follow a telephone contact protocol to perform an ongoing assessment, which is aimed at identifying caregiving issues. The care consultant and caregiver develop action steps to achieve certain goals with periodic progress evaluation. All assessments, protocol contacts, and action steps are prompted and recorded in the Care Consultation Information System computer program. The care consultant initiates phone contacts at regular intervals for 12 months making a minimum of 10 phone contacts. The first contact is made when a caregiver enrolls in the intervention, and then every 2 weeks for the first 2 months. After the first 2 months, the care consultant contacts the caregiver once per month during months 3 through 6, then every 3 months during months 7 through 12. Additionally, clients are encouraged to contact the care consultant as needed.

A.2 Coping with Caregiving

SOURCE: Gallagher-Thompson, D., Coon, D., Solano, N., Ambler, C., Rabinowitz, Y., & Thompson, L. (2003). Change in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: Site-specific results from the REACH National Collaborative Study. *The Gerontologist*, 43(4), 580–591. doi:10.1093/geront/43.4.580

PROGRAM OVERVIEW: Coping with Caregiving is a psychoeducational intervention that teaches caregivers relaxation skills, assertive communication to improve interactions with providers and others in their social networks, daily pleasant event scheduling to bolster mood and activity, ways for caregivers to appraise their loved one's behavior more realistically and intervene more appropriately, and strategies to change how caregivers think about their caregiving situations. Its goal is to help caregivers cope by reducing sources of negative feelings and bolstering sources of positive mood.

TRAINING DESCRIPTION: Training is provided to family caregivers in a group setting. Weekly 2-hour sessions take place over 10 weeks, followed by monthly booster sessions for 8 months. Interventionists are generally psychologists, social workers, or other mental health professionals. Key components of workshops include stress management, behavior problem management, communication skills, mood management strategies, and basic education about dementia and caregiving.

A.3 New York University Caregiver Intervention

SOURCE: Gaugler, J., Reese, M., & Mittelman, M. (2016). Effects of the Minnesota adaptation of NYU Caregiver Intervention on primary subjective stress of adult child caregivers of persons with dementia. *Gerontologist*, 56(3), 461–474. doi:10.1093/geront/gnu125

PROGRAM OVERVIEW: New York University Caregiver Intervention (NYUCI) has a goal of reducing negative impacts of caregiving and delaying nursing home placement for the person with dementia. The sessions focus on providing education and psychosocial support, addressing issues raised by the participants, encouraging use of social support, and improving interactions among family members. There is a strong focus on strategies for managing difficult behavior. Other family members are included to improve support for the caregiver.

TRAINING DESCRIPTION: The NYUCI program consists of four components: (1) individual counseling sessions with the primary caregiver, (2) family counseling sessions with the caregiver and other family members, (3) encouragement to attend weekly support group sessions, and (4) ongoing ad hoc contact with the counselor to provide additional information and referrals, as necessary. The six counseling sessions, conducted by master's-level psychologists, take place in the caregiver's home or another community setting over 4 to 6 months and address specific challenges that the primary caregiver or family is encountering, emphasize communication skills in conveying the caregiver's needs to others, and encourage seeking support from family and friends.

A.4 Resources for Enhancing Alzheimer's Caregiver Health

SOURCE: Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., et al. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized control trial. *Annals of Internal Medicine*, 145(10), 727–738.

Nichols, L. O., Chang, C., Lummus, A., Burns, R., Martindale-Adams, J., Graney, M. J., et al. (2008). The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. *Journal of the American Geriatrics Society*, 56(3), 413–420.
doi:10.1111/j.1532-5415.2007.01569.x

PROGRAM OVERVIEW: The overall objectives of Resources for Enhancing Alzheimer's Caregiver Health (REACH II) are to identify and reduce risk factors among family caregivers, enhance quality of care for the person with dementia, and enhance the well-being of the caregiver. The REACH II intervention focuses on five areas linked to caregiver stress: safety, self-care, social support, emotional well-being, and problem behaviors. A risk appraisal is used to determine which areas need the greatest focus.

TRAINING DESCRIPTION: Caregiver training and counseling are provided over a 6-month period in nine 1.5-hour sessions in the person's home, three half-hour telephone calls, and five telephone support group sessions. The first two sessions focus on conducting a risk assessment and instructing the caregiver in self-care and healthy behaviors. Remaining sessions are dedicated to developing the caregiver's ability to assess and manage problem behaviors and manage their own stress and well-being. The interventionist works with the caregiver to define the problem, create specific objectives, and develop an action plan. Action steps are practiced

through role-play, and caregivers report later on their use of these strategies, so the plan can be modified as needed. The training also includes practicing strategies to reduce the burden of care (e.g., taking a break from caregiving activities) and techniques for stress management such as breathing and stretching. Caregivers also practice mood management techniques and strategies for increasing pleasant events. The social support component focuses on helping caregivers receive support for decision making, managing caregiving tasks, and reducing problems with social isolation. Caregivers receive information on how to access community resources and strategies/skills related to social support and communication. The five telephone-based support group sessions reinforce the information presented during the one-on-one intervention sessions and provided caregivers an opportunity to interact with each other.

A.5 Reducing Disability in Alzheimer's Disease

SOURCE: Logsdon, R., McCurry, S., & Teri, L. (2005). A home health care approach to exercise for persons with Alzheimer's disease. *Care Management Journals*, 6(2), 90–97.
doi:10.1891/152109805780650689

Menne, H., Bass, D., Johnson, J., Primitica, B., Kearney, K., & Bollin, S., et al. (2014). Statewide implementation of “Reducing Disability in Alzheimer's Disease”: Impact on family caregiver outcomes. *Journal of Gerontological Social Work*, 57(6–7), 626–639.
<http://dx.doi.org/10.1080/01634372.2013.870276>

Teri, L., Gibbons, L., McCurry, S., Logsdon, R., Buchner, D., Barlow, W., et al. (2003, October 15). Exercise plus behavioral management in patients with Alzheimer's disease: A randomized controlled trial. *Journal of the American Medical Association*, 290(15), 2015–2022.
doi:10.1001/jama.290.15.2015

PROGRAM OVERVIEW: Reducing Disability in Alzheimer's Disease (RDAD) is designed to increase exercise and physical activity in persons with dementia and to instruct caregivers in approaches to reducing behavioral and psychological symptoms using an Antecedent-Behavior-Consequence (ABC) approach. Outcomes of interest include physical functioning, depression, and behavioral symptoms in the person with dementia.

TRAINING DESCRIPTION: RDAD sessions take place in the home of the person with dementia and include the person with dementia and the caregiver as active participants. The

interventionist—who may be a physical therapist, social worker, or other aging services professional trained in the intervention—guides the person with dementia through a series of exercises while the caregiver observes. The caregiver also is provided with dementia education and instructed in behavior management through problem-solving. Topics covered include disease symptoms and progression, home safety and environmental modifications, and legal and financial issues. Training takes place over 12, 1-hour sessions, which occur more frequently initially (two sessions per week for the first 3 weeks, then once a week for 4 weeks, then biweekly for 4 weeks).

A.6 Savvy Caregiver

SOURCE: Samia, L., Aboueissa, A., Halloran, J., & Hepburn, K. (2014). The Maine Savvy Caregiver Project: Translating an evidence-based dementia family caregiver program within the RE-AIM Framework. *Journal of Gerontological Social Work*, 57(6–7), 640–661.

<http://dx.doi.org/10.1080/01634372.2013.859201>

Kally, Z., Cote, S. D., Gonzalez, J., Villarruel, M., Cherry, D. L., Howland, S., et al. (2014, May 12). The Savvy Caregiver Program: Impact of an evidence-based intervention on the well-being of ethnically diverse caregivers. *Journal of Gerontological Social Work*, 57(6–7), 681–693. <http://dx.doi.org/10.1080/01634372.2013.850584>

PROGRAM OVERVIEW: Savvy Caregiver is a psychoeducational program designed to train family and professional caregivers in the basic knowledge, skills, and attitudes needed to handle the challenges of caring for a family member with Alzheimer's disease and to be an effective caregiver. Targeted outcomes include caregiver knowledge, confidence, self-efficacy, and depression and development of meaningful activities for the person with dementia.

TRAINING DESCRIPTION: This is a 12-hour training program that is delivered in a group setting, typically in 2-hour sessions over a 6-week period. Interventionists may come from a variety of professional backgrounds; train-the-trainer materials and resources are available. Session content covers dementia, the cognitive changes that are occurring and how they impact behaviors, establishing realistic caregiving goals, gauging the care recipient's abilities, designing appropriate activities for the person with dementia, and using a problem-solving approach to manage behavioral symptoms.

A.7 Skills2Care™

SOURCE: Gitlin, L. N., Winter, L., Corcoran, M., Dennis, M., Schinfeld, S., & Hauck, W. (2003). Effects of the Home Environmental Skill-Building Program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH Initiative. *The Gerontologist, 43*(4), 532–546. doi:10.1093/geront/43.4.532

Gitlin, L. N., Jacobs, M., & Earland, T. V. (2010b). Translation of a dementia caregiver intervention for delivery in homecare as a reimbursable Medicare service: Outcomes and lessons learned. *The Gerontologist, 50*(6), 847–854.

PROGRAM OVERVIEW: Skills2Care™ (formerly known as the Environmental Skill-building Program, or ESP) is a home-based environmental intervention designed to help family caregivers of persons with dementia modify their living space to be a more supportive environment, so that the person with dementia will exhibit fewer disruptive behaviors and experience a slower rate of decline. It is grounded in five treatment principles: client centered (areas targeted for intervention are caregiver identified), problem solving (caregivers learn how to identify concerns and strategies), tailoring (dose, intensity, and strategies are customized to person–environment configurations), action-oriented (caregivers learn skills by practicing with therapists), and cultural relevance (therapists identify values guiding care decisions to ensure appropriateness of tailored strategies).

TRAINING DESCRIPTION: There are two versions of this training: one includes up to eight in-home sessions over a period of 4 months; the other consists of five 90-minute in-home sessions and one 30-minute phone session over a period of 6 months. Based on assessments and prioritization of caregiver-identified concerns, occupational therapists tailor disease education, instruction in problem solving, and implementation of strategies. Strategies introduced include environmental simplification (decluttering and safety proofing), communication (tactile and verbal cueing), task simplification, engaging patient in activities, and stress reduction. The occupational therapist conducts a systematic needs assessment and a walk-through of the home to assess environmental factors. The occupational therapist and caregiver then work together to develop a targeted plan. Education about the disease is offered as is referral to other community resources. Strategies introduced in subsequent sessions are tailored to fit the caregiver's preferences, and the therapist and caregiver engage collaboratively to find solutions.

A.8 STAR-Community Consultants

SOURCE: Teri, L., McCurry, S. M., Logsdon, R., & Gibbons, L. E. (2005). Training community consultants to help family members improve dementia care: A randomized controlled trial. *The Gerontologist*, 45(6), 802–811. doi:10.1093/geront/45.6.802

PROGRAM OVERVIEW: STAR-C, one of the Seattle Protocols, is a behavioral intervention designed to decrease depression and anxiety in individuals with Alzheimer's disease and their family caregivers. Treatment components include general education about Alzheimer's disease, practice using a systematic approach to identifying and reducing behavior problems in dementia (the ABC model of behavior change), communication skills training, information about the relationship between mood and pleasant events, and caregiver support.

TRAINING DESCRIPTION: The intervention is delivered over a 6-month period by community clinicians with a master's degree in counseling, psychology, social work, or a related field. The interventionist meets with a family caregiver in the home once a week for 8 weeks for about an hour. In the first meeting, the consultant provides information about behavioral challenges and works with the family caregiver to identify three behavioral symptoms that are causing difficulty. In the second and third meetings, the consultant teaches the caregiver the ABC approach and helps brainstorm strategies to reduce behavioral symptoms. The remaining five meetings focus on how to communicate with a person with Alzheimer's disease, how to create pleasant events for the person, and other issues that concern the caregiver. Between meetings, caregivers record behavioral symptoms and the strategies he or she used to address them. After the in-home meetings, the consultant follows up with the caregiver through four monthly telephone calls. These calls are intended to help the caregiver develop strategies to address new behavioral symptoms. They also help to reinforce previous learnings.

A.9 Tailored Activity Program

SOURCE: Gitlin, L. N., Winter, L., Burke, J., Chernett, N., Dennis, M. P., & Hauck, W. W. (2008). Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: A randomized pilot study. *The American Journal of Geriatric Psychiatry*, 16(3), 229–239. doi:10.1097/jgp.0b013e318160da72

PROGRAM OVERVIEW: The Tailored Activity Program (TAP) seeks to reduce behavioral disturbances and depression in the person with dementia by using occupational therapy techniques to identify patients' existing abilities and previous interests and devise activities that build on them.

TRAINING DESCRIPTION: TAP includes six 90-minute home visits and two brief telephone contacts by occupational therapists over 4 months. Contacts are spaced to provide caregivers opportunities to practice using activities independently. In the first two sessions, interventionists meet with caregivers to discern daily routines and previous/current activity interests. They assess the person with dementia and the home environment and observe communication between the caregiver and person with dementia. In subsequent sessions, interventionists identify three activities and develop two- to three-page written plans for each, including an activity (completing a puzzle form board) and goal (engage in activity for 20 minutes each morning after breakfast) and specific implementation techniques. Activities are introduced through role-play or direct demonstration with the person with dementia. Caregivers are also instructed in stress-reducing techniques such as deep breathing to help establish a calm emotional tone. Caregivers practice using the activity between visits, and once an activity is mastered, another is introduced.