



# TRANSLATING INNOVATION TO IMPACT:

Evidence-based interventions to support people with Alzheimer's disease  
and their caregivers at home and in the community

**A White Paper**

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## EXECUTIVE SUMMARY

The first *National Plan to Address Alzheimer's Disease*, released in May 2012, calls for a review of the state of the art of non-pharmacological treatments and care practices for people with Alzheimer's or other dementias and their family caregivers.<sup>•</sup> The *National Plan* directs the federal government to partner with private organizations to convene a meeting of leading researchers, health care and social service professionals, and community service providers to conduct the review and make recommendations about next steps.

In response to this directive, the U.S. Administration on Aging (AoA)<sup>#</sup> partnered with the Alliance for Aging Research to convene a working meeting on June 28, 2012, with support from MetLife Foundation. This white paper presents the findings and recommendations from the meeting. It is intended to support deliberations by the Advisory Council on Alzheimer's Research, Care and Services, the U.S. Department of Health & Human Services (HHS) and other government and private organizations about how to make effective non-pharmacological treatments and care practices available to people who will benefit from them.

Findings from the June 2012 meeting indicate that the current state of the art of non-pharmacological treatments and care practices is more advanced than has previously been reported. For that reason, the state of the art is also more hopeful than might have been expected.

Research conducted in the United States shows that more than forty non-pharmacological treatments and care practices have positive effects for some people with Alzheimer's or other dementias who live in the community and some family caregivers. As discussed in this white paper, all of these treatments and care practices have been tested in randomized controlled trials (RCTs), the gold standard for rigorous scientific research. More non-pharmacological treatments and care practices are in various stages of development and evaluation. Much of this research has been conducted with funding support from the National Institute on Aging and other National Institutes of Health partners, including the National Institute on Nursing Research. In just the three months following the June 2012 meeting, RCTs conducted in the U.S. have shown positive effects for three new non-pharmacological treatments and care practices for people with these conditions and their family caregivers. Thus, it is reasonable to expect the number of such treatments and care practices will continue to grow.

In addition to RCTs, numerous studies have been conducted to test whether treatments and care practices shown to have positive effects in the highly structured context of a RCT can be delivered successfully in real-world community settings and maintain the same positive effects. In the past decade, more than fifty such studies, often referred to as translation studies, have been conducted in the U.S. These studies have been funded by AoA, primarily through the congressionally mandated Alzheimer's Disease Services and Supports Program (ADSSP), the U.S. Department of Veterans Affairs (VA), and the Rosalynn

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<sup>•</sup> The term *people with Alzheimer's or other dementias* is used in this white paper to refer to individuals who have diagnosed Alzheimer's disease, diagnosed dementia, or undiagnosed memory or cognitive impairments that are consistent with Alzheimer's disease or other dementias. The term *family caregivers* is used broadly to refer to family members, partners, friends, and neighbors who provide care for people with Alzheimer's and other dementia.

<sup>#</sup> AoA is part of the U.S. Administration for Community Living (ACL), which is a division of the U.S. Department of Health and Human Services (HHS).

Carter Institute for Caregiving and its funding partner, Johnson & Johnson. The number of translation studies funded by these government and private organizations has not been previously reported and is both surprising and impressive.

The non-pharmacological treatments and care practices that have been tested in RCTs and translation studies are not widely available in communities across the country. Participants in the June 2012 meeting reported, however, that a small but growing number of the treatments and care practices are currently available in a few communities with financial support from various sources, including out-of-pocket payment by some individuals. Examples include the following:<sup>•</sup>

- Skills<sub>2</sub>Care. Medicare is reimbursing three home health agencies for delivery of this treatment by licensed occupational therapists (through Medicare Part A). The National Family Caregiver Support Program (NFCSP) is also supporting the delivery of Skills<sub>2</sub>Care in five Area Agencies on Aging (AAA).
- Transitional Care Model (TCM) for Cognitively Impaired Elders. Two private health insurance companies, Aetna and Independence Blue Cross Blue Shield, are paying for this transitional care practice. The University of Pennsylvania Health System is providing TCM for Cognitively Impaired Elders for its members.
- Minds in Motion. Some individuals in Illinois are paying out-of-pocket for Minds in Motion, and philanthropic support has been obtained to provide scholarships for individuals who cannot afford the out-of-pocket payment.
- Savvy Caregiver. Several Alzheimer's Association chapters in California are delivering Savvy Caregiver as one of their ongoing programs. Also, a few assisted living companies in California have paid Alzheimer's Association chapters to provide Savvy Caregiver for prospective residents and families.

These examples are encouraging and suggest sources of financial support that might be available for other non-pharmacological treatments and care practices. Still, participants in the June 2012 meeting pointed out that it took a long time to obtain the current financial support. They also noted that maintaining the financial support often requires significant ongoing efforts by researchers and others, and there are substantial restrictions on eligibility for individuals to receive some of the treatments and care practices.

Further expansion and sustainability of effective non-pharmacological treatments and care practices for people with Alzheimer's or other dementias and their families will require several important next steps. As a start, participants in the June 2012 meeting emphasized the need for clearer information than is now available about the existing treatments and care practices. Although it is possible to describe any one of them, there is no accepted classification system that would allow for a more comprehensive understanding of

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<sup>•</sup> See brief descriptions of Skills<sub>2</sub>Care, TCM for Cognitively Impaired Elders, and Minds in Motion in Box 1, pgs. 10-11. Savvy Caregiver is a 12-hour group workshop, usually conducted in six 2-hour sessions, intended to provide family caregivers of people with Alzheimer's or other dementias with the knowledge, skills, and attitudes they need to perform the caregiving role successfully and manage their own stress.

the different types of treatments and care practices, the characteristics of people who benefit from them, and the kinds of problems each one has been shown to reduce or resolve. The meeting participants placed high priority on the development of such a classification system.

A research-based classification system would provide useful information for government and private organizations that fund research and translation studies on non-pharmacological treatments and care practices. The same kinds of information are needed by potential sources of financial support for the treatments and care practices, community agencies that could decide to offer them, and people with Alzheimer's or other dementias and family caregivers who could decide to use them. Participants in the June 2012 meeting pointed out, however, that the language of a research-based classification system is unlikely to be understood by or meaningful to many of these people. They noted that the classification system would provide concepts that could be adapted to create the needed information. More generally, they emphasized the importance of developing and using language and terms that are understandable and meaningful to these people in all efforts to expand the availability and use of non-pharmacological treatments and care practices.

Some findings from translation studies have been published, but many translation studies are still underway or only recently completed. Findings from these studies will provide valuable information about which treatments and care practices can be delivered successfully in community settings and what worked and did not work outside the context of a highly structured RCT. As a second "next step," participants in the June 2012 meeting recommended that findings from translation studies should be published, and therefore, made publicly available as quickly as possible. They added that findings about both successes and failures are useful in understanding what works and what does not work for particular people and problems.

Although research has resulted in treatments and care practices that show positive effects for some people with Alzheimer's or other dementias and some family caregivers, participants in the June 2012 meeting emphasized that there are important gaps. As a third "next step," they emphasized the need for additional research to develop effective treatments and care practices for particular groups of people with these conditions. In specific, they identified a need for more research on treatments and care practices that will work for people in the early and late stages of the conditions, people in racial and ethnic minority groups, people who are under age 65, and people who have non-Alzheimer's dementias. They pointed out that most existing treatments and care practices have been developed for and delivered to family caregivers and recommended research on treatments and care practices that are developed for and delivered to the person with Alzheimer's or other dementia.

The meeting participants also recommended research to develop effective treatments and care practices to address particular problems. In specific, they identified the need for additional research to address difficult behavioral symptoms, the current under-recognition and under-diagnosis of Alzheimer's and other dementias, and the lack of sufficient knowledge about how to connect people to the right treatments and care practices at the right time for them.

Despite the substantial number of completed and ongoing translation studies, participants in the June 2012 meeting stressed the need for additional studies to test the effectiveness of treatments and care practices

that have not yet been evaluated in such studies. They also noted the need for translation studies that involve larger, more diverse samples of people with Alzheimer's or other dementias and family caregivers.

Lastly, the meeting participants stressed the importance of identifying a government agency or private organization that will provide regularly updated information about findings from research and translation studies and sources of financial support for effective treatments and care practices. They noted that such an organization could also be a forum for interested researchers, community agencies, program administrators, and community service providers to discuss and resolve difficult questions that affect the viability of ongoing research and translation of research to community practice.

As noted earlier, findings from the June 2012 meeting indicate that the state of the art of non-pharmacological treatments and care practices for people with Alzheimer's or other dementias and their family caregivers is more advanced, and therefore, more hopeful than might have been expected. The current state of the art reflects sustained efforts of a large number of government and private organizations at the national, state, and local level and many individual researchers and research teams focused on finding effective ways to help people with these conditions and their family caregivers. The recommendations of the meeting participants will support the development of additional treatments and care practices to fill gaps and the creation and use of understandable and meaningful information that will help to move effective treatments and care practices from research to practice at the community level.

These treatments and care practices will neither prevent nor cure Alzheimer's or other dementias, but they will help to change the experience of people with the conditions and their family caregivers – helping them to manage and cope with the difficult situations caused by the conditions and live as well as possible despite them.

## INTRODUCTION

Over at least the past three decades, many non-pharmacological treatments and care practices have been developed to help people with Alzheimer's or other dementias and their family caregivers. As described in this white paper, 44 of these treatments and care practices have shown positive outcomes in randomized controlled trials (RCTs) conducted in the United States. The RCT is the gold standard research design for rigorous scientific evaluation, and this white paper uses the term *evidence-based* to refer to treatments and care practices that have been evaluated in one or more RCTs.

Since 2002, ten evidence-based treatments and care practices have been further tested in translation studies conducted in the United States. The translation studies are intended to determine whether the evidence-based treatments and care practices can be implemented successfully and result in the same positive outcomes when they are provided outside the highly structured context of a RCT.

Despite the substantial number of evidence-based non-pharmacological treatments and care practices, most are not well known except to the researchers, clinicians, and community service providers who developed and implemented them and the public and private organizations that funded their development, implementation, and evaluation. The translation studies are even less well known. Moreover, although several of the treatments and care practices are currently available to people with Alzheimer's or other dementias and their family caregivers in a few health care systems and localities, none are widely available in communities across the country.

The first *National Plan to Address Alzheimer's Disease*, released in May 2012, identifies the need to “review the state of the art of evidence-based interventions that can be delivered by community-based organizations.”<sup>1</sup> The *National Plan* further directs the U.S. Department of Health and Human Services (HHS) to partner with private organizations to convene a meeting of leading researchers, clinicians, and community service providers to review research and translational activities related to evidence-based interventions and develop a white paper “outlining strategies for identifying promising interventions for research, translation, and expansion into practice at the community level.”

To respond to the *National Plan* directive, the U.S. Administration on Aging (AoA) partnered with the Alliance for Aging Research to convene a working meeting on June 28, 2012 in Washington DC, with support from MetLife Foundation. Forty invited participants attended the meeting, including researchers, medical care and community service providers, representatives of provider and advocacy associations, and staff of federal government agencies with responsibilities for research on treatments and care practices for people with Alzheimer's or other dementias and their family caregivers and translation of research to practice.

Nine invited presentations described non-pharmacological treatments and care practices (referred to as “interventions” in the meeting materials) that are currently in various stages of implementation, evaluation, translation, and expansion into the community, including:

- two that are in the initial stages of implementation and evaluation;



- seven that have shown positive results in published RCTs; five of these are now being tested in translation projects, and two are available to people in a few health care systems and communities; and
- two that have shown positive results in RCTs which are not yet published.

Discussion at the meeting focused on barriers to the development, evaluation, delivery, and use of non-pharmacological treatments and care practices and recommended steps to overcome those barriers.

The meeting agenda and list of participants are shown in Appendix A. The treatments and care practices presented at the meeting are described briefly in Box 1. Information provided by the presenters before the meeting, including descriptions of the treatments and care practices, is shown in Appendix B, and the references are shown in Appendix C. A videocast of the meeting is available on the Alliance for Aging Research website.<sup>2</sup>

This white paper presents information, observations, and recommendations from the June 2012 meeting and additional analyses of peer-reviewed literature about non-pharmacological treatments and care practices for people with Alzheimer’s or other dementias. It responds to the directive of the *National Plan To Address Alzheimer’s Disease*, described earlier, and is intended to support deliberations of the Advisory Council on Alzheimer’s Research, Care and Services, HHS, and others about how to make effective non-pharmacological treatments and care practices available to people who need them. This white paper discusses:

- the current status of evidence-based, non-pharmacological treatments and care practices for people with Alzheimer’s or other dementias and their family caregivers;
- translation studies that have been conducted to test the feasibility and effectiveness of evidence-based treatments and care practices in community settings;
- expansion and sustainability of evidence-based treatments and care practices in the community;
- the need for mechanisms to make the right evidence-based treatments and care practices available to individuals with Alzheimer’s or other dementias and their family caregivers at the right time, and using delivery methods that work for them; and
- recommendations for next steps.

The white paper focuses on treatments and care practices that have been developed and evaluated in the United States. Additional treatments and care practices for people with Alzheimer’s or other dementias and their family caregivers have been developed and evaluated in other countries. These other treatments and care practices may provide useful ideas to fill gaps in the existing evidence-based treatments and care practices in this country.

## **Box 1. Non-Pharmacological Treatments and Care Practices for People with Alzheimer’s or Other Dementias that were Presented at the June 2012 Meeting**

**MeetUp & Mentor** is intended to provide meaningful connections among people with mild cognitive impairment or early dementia. People with these conditions join a group that offers and supports monthly social gatherings and on-line personal connections among group members. Trained peer mentors with mild cognitive impairment or early dementia contact individuals who express interest in the group and invite them to join the social gatherings and online “Memory MeetUp.” Mentors are also available to talk one-on-one with group members who request a peer mentor.

**Minds in Motion** is intended to improve or sustain cognitive and physical functioning and self-esteem in people with mild cognitive impairment or early dementia. People with these conditions join a group that meets once a week for 16 to 20 weeks and on a continuing basis. Group meetings include cognitive training, Tai Chi and other physical activities, creative writing, art, and photography, all conducted in an atmosphere intended to support normalization.

**Reducing Disability in Alzheimer’s Disease (RDAD)** is intended to increase exercise and physical activity and reduce behavioral and psychological symptoms in people with dementia at any stage who are physically able to participate in exercise. In 12 weekly, one-hour sessions in the person’s home, the family caregiver is taught ways to reduce symptoms, such as anxiety, depression, and agitation, and encourage and help the person with aerobic, strength training and endurance exercises to improve balance, flexibility, and physical functioning.

**New York University Caregiver Intervention (NYUCI)** is intended to increase spouse caregivers’ emotional and physical well-being and ability to provide care at home for their spouse with Alzheimer’s disease at any stage and to avoid or postpone nursing home placement. Counseling is provided over a 4-month period in 6 in-person sessions with the spouse caregiver in the person’s home or another community setting. To increase support for the spouse caregiver, 4 of the 6 sessions also include one or more other family members or friends. The spouse caregiver is encouraged to join a support group and can initiate additional telephone counseling as needed.

**Skills2Care** is intended to decrease feelings of burden and increase well-being in family caregivers of people with dementia at any stage, except people who are bedridden and unresponsive to touch, and to increase caregivers’ skills and confidence in their caregiving abilities. Caregiver training and counseling are provided over a 2- to 6-month period in 6 to 10 sessions in the person’s home and 3 follow-up telephone calls. The training and counseling focus on ways to reduce care-related problems, such as simplifying tasks for the person, increasing support from other relatives and friends, modifying the home to increase safety, and helping caregivers take care of themselves.

**Memory Club** is intended to provide an emotionally safe environment where people with early memory loss and a *care partner* (a family member or friend) can learn more about memory loss conditions and develop confidence about how to cope and live well with the conditions. People with these conditions and their care partners meet once a week for 10 weeks. The groups meet together for the first hour, which is focused on information. They meet separately for the second hour to talk about their experiences and feelings and develop supportive relationships.

**Box 1. Non-Pharmacological Treatments and Care Practices for People with Alzheimer’s or Other Dementias That Were Presented at the June 2012 Meeting (cont.)**

**Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II)** is intended to reduce depression and improve quality of life for family caregivers of people with dementia at any stage, except people who are bedridden, and to avoid or postpone nursing home placement. Caregiver training and counseling are provided over a 6-month period in 9 sessions in the person’s home, 3 telephone calls, and 5 telephone support group sessions. The training and counseling focus on ways to manage the person’s challenging behaviors, reduce the caregiver’s negative emotional response to the behaviors, manage the caregiver’s stress, and increase support from other relatives and friends.

**BRI (Benjamin Rose Institute) Care Counseling** is intended to improve depression, stress, and feelings of isolation for people with dementia and their family caregivers, reduce care-related strain between them, and reduce feelings of embarrassment and inability to cope for the person with dementia. Counseling, emotional support, and assistance with problem identification, problem solving and connection to community services are provided over a one-year period in 10 or more telephone sessions, including calls every two weeks for the first two months, at one-month intervals for the next four months, at 3-month intervals for the next six months, and as needed in between.

**Collaborative Care Model for Alzheimer’s Disease and Related Dementias** is intended to improve quality of care for people with dementia at any stage, reduce their behavioral and psychological symptoms and reduce stress in their family caregivers. Care management, education, and support are provided over a one-year period in six in-person sessions at a medical clinic, once a month for the first 3 months and at 3-month intervals for the next 9 months, and telephone calls initiated as needed by the family caregiver. Monthly group meetings are provided at the clinic, focusing on education and support for the caregivers and exercise for the people with dementia.

**Transitional Care Model (TCM) for Cognitively Impaired Elders** is intended to improve transitions from hospital to home, reduce associated functional decline, readmissions, and nursing home placement, and decrease mortality for people with cognitive impairment and dementia at any stage. Beginning in the hospital and continuing with visits in the person’s home and ongoing in-person and telephone contacts for about 2 months, the person and the family caregiver receive information, support, counseling, and help with coordinating care from the person’s medical providers, managing medications, problem solving, and arranging needed community services.

**Partners In Dementia Care** is intended to provide care coordination and reduce unmet medical and non-medical care needs for people with dementia at any stage and their family caregivers. Information, emotional support, connection to medical and non-medical services, and help to increase support from other relatives and friends are provided by telephone through a working partnership between care coordinators based in a medical clinic and a community agency. After a care plan is developed, monitoring is provided through biweekly calls for the first 3 months and monthly calls on an ongoing basis.

This white paper focuses on treatments and care practices intended for people with Alzheimer’s or other dementias who live in the community. It does not include treatments and care practices specifically intended for use in nursing homes, assisted living or other residential care facilities, adult day centers, hospitals, or inpatient rehabilitation centers. Again, however, these other treatments and care practices may provide useful ideas to fill gaps in the existing treatments and care practices for people who live in the community.

One strong recommendation of participants in the June 2012 meeting was to develop and use language and terms that are understandable and meaningful to people who make decisions about funding, providing, and using evidence-based treatments and care practices. The meeting participants pointed out that the term *interventions*, which is widely used to refer to the non-pharmacological approaches discussed in the meeting, is unlikely to be either understandable or meaningful to most of the people who are making or will make these decisions.

Some meeting participants recommended using the term *treatments* instead of *interventions*. They argued that the existing non-pharmacological approaches to care for people with Alzheimer’s or other dementias are at least as effective as the available medications for these people and that referring to these approaches as *treatments* conveys the message that they should be considered in the same way as medications by anyone who is making decisions about care for such people.

Other meeting participants argued that the term *treatments* “over-medicalizes” Alzheimer’s and dementia care. They recommended using the term *care practices* because it conveys the message that people with these conditions need both medical and non-medical care and services.

In response to these recommendations, this white paper uses the term *treatments and care practices* instead of the term *interventions* to refer to non-pharmacological approaches to care for people with Alzheimer’s or other dementias and their families. Although using both terms, *treatments and care practices*, is sometimes cumbersome, the white paper does so to retain and emphasize the two different perspectives expressed by the meeting participants.

## CURRENT STATUS OF EVIDENCE-BASED, NON-PHARMACOLOGICAL TREATMENTS AND CARE PRACTICES

Since 1993, randomized controlled trials (RCTs) conducted in the United States have shown positive outcomes for at least 44 non-pharmacological treatments and care practices for people with Alzheimer's or other dementias who live in the community and their family caregivers. Table 1 shows these treatments and care practices, which include the evidence-based treatments and care practices presented at the June 2012 meeting (marked with an asterisk in the table) and additional evidence-based treatments and care practices that were identified in compendia prepared by RTI for AoA,<sup>3,4</sup> the online "Caregiver Intervention Database" developed by the Rosalynn Carter Institute for Caregiving,<sup>5</sup> published literature reviews,<sup>6,7,8,9,10,11,12,13,14,15,16</sup> and advance access journal websites.

Table 1 shows a few features of the 44 evidence-based treatments and care practices: 1) the primary intended recipient (the person, the family caregiver, or the *dyad*, i.e., both the person and the family caregiver); 2) the identified disease or condition of the person; 3) the stage of the person's disease or condition; 4) where the treatment or care practice was delivered (in the person's home, a community setting, medical setting, or workplace); and 5) how it was delivered (in-person, by telephone, by computer, or other). As discussed later, many additional features could be used to describe and differentiate these treatments and care practices.

The treatments and care practices listed in Table 1 include most, but probably not all, of the non-pharmacological treatments and care practices that have shown positive outcomes in one or more RCTs conducted in the United States. Additional treatments and care practices are in various stages of development, implementation, and evaluation. In July 2012, positive outcomes from a RCT of a care practice called Maximizing Independence at Home (MIND at Home) were announced at the Alzheimer's Association International Conference.<sup>17</sup> In the next two months, positive outcomes from RCTs of two other treatments, ANSWERS and Mindfulness-Based Stress Reduction for Caregivers, were accepted for publication.<sup>18,19</sup> Thus, it is reasonable to expect the number of evidence-based treatments and care practices will continue to grow.

Each of the treatments and care practices listed in Table 1 has been evaluated in at least one RCT and shown to have positive outcomes for the sample members intended to receive the treatments and care practices or at least one subgroup of those sample members. For example, the Minnesota Family Workshop (MFW) (number 7 in Table 1) was evaluated in one RCT which showed that family caregivers who participated in MFW group meetings were more likely than family caregivers who did not participate in the group meetings to say their relative's behavioral symptoms had decreased. Caregivers who participated in the MFW group meetings also said they reacted less to the person's behavioral symptoms and had reduced feelings of depression and burden.<sup>39</sup> Further analysis of the RCT findings showed that these positive outcomes were associated with the new knowledge, skills, and beliefs about caregiving obtained by the caregivers through participation in the MFW.<sup>40</sup>

**Table 1. Evidence-Based Non-Pharmacological Treatments and Care Practices for People with Alzheimer’s or Other Dementias Who Live in the Community and Their Family Caregivers, by Selected Characteristics, United States, 2012.**

**Table 1a. Primary Targeted Recipient**

Treatments and Care Practices	Person with Dementia	Family Caregiver	dyad <sup>r</sup>
1. New York University Caregiver Intervention (NYUCI)* 20,21,22,23,24,25,26,27,28,29,30,31,32	—	X spouse co-resident + one other family member	—
2. Behavioral treatment of depression in dementia 33	—	—	X
3. Reducing Disability in Alzheimer’s Disease (RDAD)* 34	—	—	X
4. STAR-Caregiver (STAR-C) 35	—	X	—
5. Nighttime Insomnia Treatment and Education for Alzheimer’s Disease (NITE-AD) 36	—	—	X
6. Progressively Lowered Stress Threshold (PLST) 37,38	—	X	—
7. Minnesota Family Workshop 39,40	—	X + one other family member	—
8. Partners in Caregiving 41	—	X	—
9. Anger and Depression Management 42	—	X	—
10. Coping with Caregiving (CWC) (REACH I) 43,44	—	X female co-resident	—
11. In-Home Behavioral Management Program (IHBMP) 45	—	X female	—
12. Skills2Care* 46,47,48,49,50	—	X co-resident	—
13. Tailored Activity Program (TAP) 51,52	—	X co-resident	—
14. Advancing Caregiver Training (ACT) 53	—	X co-resident	—
15. Care of Persons with Dementia in their Environments (COPE) 54	—	X	—
16. Telephone support group 55	—	X female	—
17. Skills Training or minimal support (REACH I) 56	—	X co-resident	—
18. Behavior management alone or with stress and coping (REACH I) 57,58	—	X co-resident	—
19. Family therapy and computer-telephone integrated system (REACH I) 59	—	X co-resident + other family member	—
20. Automated telephone support (REACH I) 60	—	X	—
21. Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II)* 61,62,63	—	X	—
22. BRI Care Counseling* 64,65	—	—	X
23. Collaborative Care Model for Alzheimer’s Disease and Related Dementias* 66	—	—	X

(continued)

**Table 1a. Primary Targeted Recipient (continued)**

Treatments and Care Practices	Person with Dementia	Family Caregiver	dyad <sup>f</sup>
24. Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) <sup>67</sup>	—	—	X
25. Dementia Care Consultation for Family Caregivers <sup>68</sup>	—	X	—
26. Tailored Caregiver Assessment and Referral (T-CARE <sup>®</sup> ) <sup>69</sup>	—	X	—
27. Maximizing Independence at Home (MIND at Home) <sup>φ</sup> <sub>17</sub>	—	—	X
28. Partners in Dementia Care (PDC)* <sup>φ 70,71</sup>	—	—	X
29. Minds in Motion* <sup>72,73</sup>	—	—	X
30. Early-Stage Memory Loss Support Group <sup>74</sup>	X	—	—
31. Transitional Care Model (TCM) for Cognitively Impaired Elders* <sup>φ 75,76</sup>	—	—	X
32. Nurseline Video-Assisted Modeling Program <sup>77</sup>	—	X co-resident	—
33. Behavior management and coping skills training for spouses <sup>78</sup>	—	X spouse co-resident + other informal family member/ friend/ neighbor	—
34. Information and support and skill building treatments <sup>79,80</sup>	—	X	—
35. Brief occupational therapy intervention <sup>81</sup>	—	—	X
36. Cognitive-behavioral therapy <sup>82</sup>	—	X	—
37. Caregiver's Friend: Dealing with Dementia <sup>83</sup>	—	X	—
38. Project CARE <sup>84</sup>	—	X	—
39. Distance-based Interventions for male caregivers <sup>85</sup>	—	X male co-resident	—
40. Family Intervention: Telephone Tracking-Dementia (FITT-D) <sup>86</sup>	—	X	—
41. Complementary and alternative medicine (CAM) Therapy for Stress Reduction <sup>87</sup>	—	X	—
42. Peaceful Mind Program <sup>88</sup>	X	—	—
43. Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS) <sup>18</sup>	—	—	X
44. Mindfulness-Based Stress Reduction for Caregivers <sup>19</sup>	—	X	—

**Table 1b. Person's Condition and Stage of the Condition**

<b>Treatments and Care Practices</b>	<b>Person's Condition</b>	<b>Stage of the Condition</b>
1. New York University Caregiver Intervention (NYUCI)*	diagnosed Alzheimer's disease	not specified
2. Behavioral treatment of depression in dementia	diagnosed probable Alzheimer's disease	not specified
3. Reducing Disability in Alzheimer's Disease (RDAD)*	diagnosed probable or possible Alzheimer's disease	any stage if ambulatory
4. STAR-Caregiver (STAR-C)	diagnosed probable or possible Alzheimer's disease	moderate stage
5. Nighttime Insomnia Treatment and Education for Alzheimer's Disease (NITE-AD)	diagnosed Alzheimer's disease	any stage if ambulatory
6. Progressively Lowered Stress Threshold (PLST)	diagnosed ADRD or memory impairment	not specified
7. Minnesota Family Workshop	diagnosed dementia	any except very late
8. Partners in Caregiving	diagnosed dementia	not specified
9. Anger and Depression Management	diagnosed dementia	not specified
10. Coping with Caregiving (CWC) (REACH I)	diagnosed dementia or MMSE<24 or memory problems	not specified
11. In-Home Behavioral Management Program (IHBMP)	diagnosed dementia MMSE<24	any except very late
12. Skills <sub>2</sub> Care*	diagnosed ADRD or MMSE<24	any except very late
13. Tailored Activity Program (TAP)	diagnosed dementia or MMSE<24	any except very late
14. Advancing Caregiver Training (ACT)	diagnosed dementia or MMSE<24	any except very late
15. Care of Persons with Dementia in their Environments (COPE)	diagnosed dementia or MMSE<24	any except very late
16. Telephone support group	diagnosed dementia	not specified
17. Skills Training or minimal support (REACH I)	diagnosed ADRD or MMSE<24	not specified
18. Behavior management alone or with stress and coping (REACH I)	diagnosed ADRD or MMSE<24	not specified
19. Family therapy and computer-telephone integrated system (REACH I)	diagnosed ADRD or MMSE<24	not specified
20. Automated telephone support (REACH I)	diagnosed Alzheimer's disease or cognitive impairment with MMSE<24	not specified
21. Resources for Enhancing Alzheimer's Caregiver Health II (REACH II)*	diagnosed ADRD or MMSE<24	any except very late
22. BRI Care Counseling*	diagnosed dementia or symptom code for memory loss	not specified
23. Collaborative Care Model for Alzheimer's Disease and Related Dementias*	diagnosed Alzheimer's disease	not specified
24. Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS)	diagnosed dementia	not specified
25. Dementia Care Consultation for Family Caregivers	diagnosed dementia	any stage if ambulatory

(continued)



**Table 1b. Person’s Condition and Stage of the Condition (continued)**

<b>Treatments and Care Practices</b>	<b>Person’s Condition</b>	<b>Stage of the Condition</b>
26. Tailored Caregiver Assessment and Referral (T-CARE®)	cognitive impairment	not specified
27. Maximizing Independence at Home (MIND at Home) <sup>ϕ</sup>	diagnosed dementia, MCI or other memory disorder	not specified
28. Partners in Dementia Care (PDC)* <sup>ϕ</sup>	diagnosed dementia	not specified
29. Minds in Motion*	diagnosed dementia	early and early-middle stage
30. Early-Stage Memory Loss Support Group	diagnosed dementia and MMSE>18	early stage
31. Transitional Care Model (TCM) for Cognitively Impaired Elders* <sup>ϕ</sup>	history of dementia, delirium or positive screen for cognitive impairment	not specified
32. Nurseline Video-Assisted Modeling Program	dementia MMSE<21	moderate stage
33. Behavior management and coping skills training for spouses	diagnosed Alzheimer’s disease or MMSE<21	not specified
34. Information and support and skill building treatments	diagnosed Alzheimer’ disease or dementia	moderate stage
35. Brief occupational therapy intervention	diagnosed Alzheimer’s disease	mild or moderate stage
36. Cognitive-behavioral therapy	diagnosed Alzheimer’s disease	not specified
37. Caregiver’s Friend: Dealing with Dementia	substantial memory problems	not specified
38. Project CARE	diagnosed Alzheimer’s disease	mild or moderate stage
39. Distance-based Interventions for male caregivers	diagnosed dementia	not specified
40. Family Intervention: Telephone Tracking-Dementia (FITT-D)	diagnosed dementia	mild or moderate stage
41. Complementary and alternative medicine (CAM) Therapy for Stress Reduction	dementia	not specified
42. Peaceful Mind Program	diagnosed dementia	mild or moderate stage
43. Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS)	diagnosed dementia or memory loss	mild or moderate stage
44. Mindfulness-Based Stress Reduction for Caregivers	memory loss consistent with dementia	Not specified

**Table 1c. Where the Treatment or Care Practice Was Delivered<sup>8</sup>**

Treatments and Care Practices	Home	Community	Medical	Work Place
1. New York University Caregiver Intervention (NYUCI)*	X	X	X	—
2. Behavioral treatment of depression in dementia	X	—	—	—
3. Reducing Disability in Alzheimer's Disease (RDAD)*	X	—	—	—
4. STAR-Caregiver (STAR-C)	X	—	—	—
5. Nighttime Insomnia Treatment and Education for Alzheimer's Disease (NITE-AD)	X	—	—	—
6. Progressively Lowered Stress Threshold (PLST)	X	—	—	—
7. Minnesota Family Workshop	—	various community settings	—	—
8. Partners in Caregiving	—	various community settings	—	—
9. Anger and Depression Management	—	various community settings	—	—
10. Coping with Caregiving (CWC) (REACH I)	—	various community settings	—	—
11. In-Home Behavioral Management Program (IHBMP)	X	—	—	—
12. Skills <sub>2</sub> Care*	X	—	—	—
13. Tailored Activity Program (TAP)	X	—	—	—
14. Advancing Caregiver Training (ACT)	X	—	—	—
15. Care of Persons with Dementia in their Environments (COPE)	X	—	—	—
16. Telephone support group	—	—	—	—
17. Skills Training or minimal support (REACH I)	X	—	—	—
18. Behavior management alone or with stress and coping (REACH I)	—	—	X primary care	—
19. Family therapy and computer-telephone integrated system (REACH I)	X	—	—	—
20. Automated telephone support (REACH I)	—	—	—	—
21. Resources for Enhancing Alzheimer's Caregiver Health II (REACH II)*	X	—	—	—
22. BRI Care Counseling*	—	—	—	—
23. Collaborative Care Model for Alzheimer's Disease and Related Dementias*	—	—	X primary care	—
24. Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS)	X	—	—	—
25. Dementia Care Consultation for Family Caregivers	X	—	X primary care	—

(continued)

**Table 1c. Where the Treatment or Care Practice Was Delivered<sup>δ</sup> (continued)**

Treatments and Care Practices	Home	Community	Medical	Work Place
26. Tailored Caregiver Assessment and Referral (T-CARE <sup>®</sup> )	—	—	—	—
27. Maximizing Independence at Home (MIND at Home) <sup>ϕ</sup>	X	X various settings including adult day centers	X hospital, rehab center, doctor's office	—
28. Partners in Dementia Care (PDC) <sup>* ϕ</sup>	—	—	—	—
29. Minds in Motion <sup>*</sup>	—	X church	—	—
30. Early-Stage Memory Loss Support Group	—	X various settings	—	—
31. Transitional Care Model (TCM) for Cognitively Impaired Elders <sup>* ϕ</sup>	X	—	X Hospital, doctor's office	—
32. Nurseline Video-Assisted Modeling Program	X	—	—	—
33. Behavior management and coping skills training for spouses	X	X university	—	—
34. Information and support and skill building treatments	—	X	—	—
35. Brief occupational therapy intervention	X	—	—	—
36. Cognitive-behavioral therapy	—	—	—	—
37. Caregiver's Friend: Dealing with Dementia	—	—	—	—
38. Project CARE	—	—	—	—
39. Distance-based Interventions for male caregivers	—	—	—	—
40. Family Intervention: Telephone Tracking-Dementia (FITT-D)	—	—	—	—
41. Complementary and alternative medicine (CAM) Therapy for Stress Reduction	—	—	X health clinics	—
42. Peaceful Mind Program	X	—	—	—
43. Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS)	X	—	—	—
44. Mindfulness-Based Stress Reduction for Caregivers	—	X	—	—

**Table 1d. How the Treatment or Care Practice Was Delivered<sup>8</sup>**

Treatments and Care Practices	In-person	Telephone	Computer	Other
1. New York University Caregiver Intervention (NYUCI)*	X	X	—	support group
2. Behavioral treatment of depression in dementia	X	—	—	—
3. Reducing Disability in Alzheimer's Disease (RDAD)*	X	—	—	—
4. STAR-Caregiver (STAR-C)	X	X	—	—
5. Nighttime Insomnia Treatment and Education for Alzheimer's Disease (NITE-AD)	X	—	—	—
6. Progressively Lowered Stress Threshold (PLST)	X	X	—	caregiver notebook
7. Minnesota Family Workshop	X in a group	—	—	—
8. Partners in Caregiving	X in a group	—	—	—
9. Anger and Depression Management	X in a group	—	—	—
10. Coping with Caregiving (CWC) (REACH I)	X in a group	—	—	—
11. In-Home Behavioral Management Program (IHBMP)	X	—	—	—
12. Skills <sub>2</sub> Care*	X	X	—	—
13. Tailored Activity Program (TAP)	X	X	—	—
14. Advancing Caregiver Training (ACT)	X	X	—	—
15. Care of Persons with Dementia in their Environments (COPE)	X	X	—	—
16. Telephone support group	—	X group	—	—
17. Skills Training or minimal support (REACH I)	X indiv. + in a group	X	—	TV, VCR, videos
18. Behavior management alone or with stress and coping (REACH I)	X	X	—	12 info pamphlets
19. Family therapy and computer-telephone integrated system (REACH I)	X	computer-telephone integrated system (CTIS) installed in family home	access to long-distance to reach other family members	—
20. Automated telephone support (REACH I)	—	integrated telephone network system and interactive voice response (IVR) computer network system	—	—

(continued)

**Table 1d. How the Treatment or Care Practice Was Delivered<sup>8</sup> (continued)**

Treatments and Care Practices	In-person	Telephone	Computer	Other
21. Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II)*	X	X	—	—
22. BRI Care Counseling*		X	X	—
23. Collaborative Care Model for Alzheimer’s Disease and Related Dementias*	X	X	—	—
24. Alzheimer’s Disease Coordinated Care for San Diego Seniors (ACCESS)	X	X	—	—
25. Dementia Care Consultation for Family Caregivers	X	X	—	—
26. Tailored Caregiver Assessment and Referral (T-CARE <sup>®</sup> )	X	X	—	—
27. Maximizing Independence at Home (MIND at Home) <sup>ϕ</sup>	X	X	X	Fax
28. Partners in Dementia Care (PDC)* <sup>ϕ</sup>	—	X	X	—
29. Minds in Motion*	X in a group	—	—	—
30. Early-Stage Memory Loss Support Group	X in a group	—	—	—
31. Transitional Care Model (TCM) for Cognitively Impaired Elders* <sup>ϕ</sup>	X	X	—	—
32. Nurseline Video-Assisted Modeling Program	—	X	—	videos modeling caregiver behavior
33. Behavior management and coping skills training for spouses	X indiv. + in a group	—	—	
34. Information and support and skill building treatments	X in a group	X	—	—
35. Brief occupational therapy intervention	X	—	—	—
36. Cognitive-behavioral therapy	X in a group	—	—	—
37. Caregiver’s Friend: Dealing with Dementia	—	—	X inter-active video	—
38. Project CARE	X in a group	—	—	—
39. Distance-based Interventions for male caregivers	—	X	—	mailed booklets and video
40. Family Intervention: Telephone Tracking-Dementia (FITT-D)	—	X	—	—
41. Complementary and alternative medicine (CAM) Therapy for Stress Reduction	X	—	—	—

(continued)

**Table 1d. How the Treatment or Care Practice Was Delivered<sup>δ</sup> (continued)**

Treatments and Care Practices	In-person	Telephone	Computer	Other
42. Peaceful Mind Program	X	X	—	—
43. Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS)	X	—	—	—
44. Mindfulness-Based Stress Reduction for Caregivers	X In a group	X	—	—

<sup>†</sup> The term *dyad* means both the person with dementia and the family caregiver.

<sup>δ</sup> Information about where the treatment or care practice was delivered and how it was delivered pertains to the procedures used in the original RCT(s).

\* Treatment or care practice was presented at the June 2012 meeting.

ϕ The RCT for the treatment or care practice has not yet been published.

The superscript notation(s) following each treatment or care practice in Table 1a refer to the RCT(s) that found statistically significant positive outcomes for the treatment or care practice and any additional peer-reviewed studies that used data from the same RCT(s) and found other positive outcomes or factors associated with positive outcomes found in those RCT(s). The statistical significance of the positive outcomes reported for the treatments and care practices in the table was defined by standards set by the researchers who conducted the relevant RCT(s) and reported the results. Therefore, the standards of statistical significance vary across the RCTs referenced in the table. Other methodological characteristics that may affect the scientific rigor and quality of the RCTs also vary.

Coping with Caregiving (CWC) (number 10 in Table 1) was evaluated in one RCT which showed that female family caregivers who participated in the CWC group meetings were more likely than female family caregivers who did not participate in the CWC group meetings to have reduced feelings of depression, increased use of adaptive coping strategies, and decreased use of negative coping strategies.<sup>43</sup> Further analysis of the RCT findings showed that among the female family caregivers who participated in the CWC group meetings, those who started out with lower levels of self-confidence about their ability to manage caregiving situations were more likely than those who started out with higher levels of confidence to benefit from the treatment.<sup>44</sup>

### Observations from the June 2012 meeting and literature review

**1. There are now a substantial number of evidence-based non-pharmacological treatments and care practices for people with Alzheimer’s or other dementias and their family caregivers; however, they are not well known.**

Forty-four different treatments and care practices are included in Table 1. Despite published articles about many of these treatments and care practices and literature reviews that include them, the treatments and care practices are not well known. It is sometimes assumed that there are few, if any, non-pharmacological treatments and care practices for people with Alzheimer’s or other dementias and their family caregivers. Discussion at the June 2012 meeting and review of the research literature indicate that this assumption is not correct. Certainly there are gaps in needed research and differences in the scientific rigor and quality of the available RCTs, and the existing evidence-based treatments and care practices are not widely available. It is important to recognize, however, that a substantial and growing number of non-pharmacological treatments and care practices have been shown to help at least some people with Alzheimer’s or other dementias and their family caregivers.

2. **Some of the treatments and care practices have been available for more than a decade.**

The first three articles reporting positive outcomes from RCT data on the New York University Caregiver Intervention (NYUCI) were published between 1993 and 1996.<sup>20,21,22</sup> RCT data for five other non-pharmacological treatments and care practices shown in Table 1 were published before 2002:

- Behavioral treatment of depression in dementia;<sup>33</sup>
- Progressively Lowered Stress Threshold;<sup>37</sup>
- Minnesota Family Workshop;<sup>39,40</sup>
- Skills<sub>2</sub>Care, previously called Environmental Skill Building;<sup>46</sup> and
- Nurseline Video-Assisted Modeling Program.<sup>77</sup>

3. **Some research teams have developed, evaluated, and found positive outcomes for several of these treatments and care practices.**

Research teams have often started with observations and hypotheses about how Alzheimer's and other dementias negatively affect the health and well-being of people with the conditions and their family caregivers. The teams have then designed and tested treatments and care practices intended to reduce those negative effects, used their findings and findings from other researchers to revise and refine the treatments and care practices, and then re-evaluated them. Over time, this iterative process has resulted in increasingly well-validated and targeted treatments and care practices.

One such research team is based at the University of Washington in Seattle. Five of the evidence-based treatments and care practices included in Table 1 were developed, evaluated, and published by this team over the past 15 years (numbers 2, 3, 4, 5, and 30 in the table). The team refers to its work as the "*Seattle Protocols*."<sup>89</sup> One of the team's evidence-based treatments, RDAD, was presented at the June 2012 meeting, and RDAD and STAR-C are being tested in translation studies in Ohio and Oregon. In April 2012, the team received 5-year funding through a joint National Institute on Aging (NIA)/AoA grant program, *Translational Research to Help Older Adults Maintain their Health and Independence in the Community*. The funded study will test RDAD in Area Agencies on Aging (AAAs) in Washington state and Oregon.<sup>90</sup>

A second example is a research team based at Thomas Jefferson University in Philadelphia that developed, evaluated, and published five of the other evidence-based treatments and care practices included in Table 1 (numbers 12, 13, 14, 15, and 16 in the table). Skills<sub>2</sub>Care, which was presented at the June 2012 meeting, is the latest iteration of a treatment that was first shown to have positive outcomes in a RCT published by this team in 2001.<sup>46</sup> The treatment has been evaluated in four other RCTs and numerous translation projects since then and is currently reimbursed by Medicare when provided by licensed occupational therapists in a few health care systems in specified circumstances.<sup>91</sup>

Many research teams worked together in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project, which was funded by NIA beginning in 1995. In the first phase of the project (REACH I), six research teams implemented different treatments and care practices that were evaluated in RCTs using exactly the same outcome measures.<sup>92</sup> Each team found positive outcomes for at least one

subgroup of its sample members.<sup>43,47,56,57,59,60</sup> In the second phase of the project (REACH II), the research teams and the REACH coordinating center at the University of Pittsburgh developed a treatment that combined successful components of the six REACH I treatments to create the REACH II treatment. REACH II was implemented by five of the six REACH I teams and also found to have positive outcomes in this multi-site RCT.<sup>61</sup>

Following REACH II, many of the researchers from the coordinating center and the REACH I and II teams conducted REACH-related studies. Some conducted additional analyses of RCT data from REACH I or II.<sup>58,62,63,93</sup> Others conducted studies to translate REACH I and REACH II treatments to community practice.<sup>94,95, 96,97</sup>

In 2006, when the findings from REACH II<sup>61</sup> and another evidence-based non-pharmacological treatment/care practice, Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS),<sup>67</sup> were published in the same issue of the *Annals of Internal Medicine*, an editorial in the issue commented:

*If these interventions were drugs, it is hard to believe that they would not be on the fast track to approval. The magnitude of benefit and quality of evidence supporting these interventions considerably exceed those of currently approved pharmacological therapies for dementia.*<sup>98</sup>

## **Issues and Concerns from the June 2012 Meeting**

Participants in the June 2012 meeting identified five important issues and concerns about the current status and future prospects for research in this area.

### **1. Lack of sufficient and sustained funding for research to develop, implement, and evaluate non-pharmacological treatments and care practices**

Over at least the past 30 years, federal government agencies have provided some funding for the development, implementation, and evaluation of non-pharmacological treatments and care practices for people with Alzheimer's or other dementias and their family caregivers. Non-federal sector participants at the June 2012 meeting pointed out, however, that federal agencies have focused most of their Alzheimer's and dementia-related research funding on studies about the causes of the conditions and medications to prevent and treat them. They also noted that the amount of federal government funding for research on non-pharmacological treatments and care practices for people with these conditions has varied from year-to-year.

Some private foundations and associations have provided funding for development, implementation, and evaluation of non-pharmacological treatments and care practices for people with Alzheimer's or other dementias and their family caregivers. Funding from these sources has also varied over time as a result of changes in the resources and funding priorities of particular foundations and associations.

Limitations in the amount and consistency of available funding have often made it difficult to sustain the iterative process of development, testing, refinement and re-evaluation that has resulted in many of the



existing treatments and care practices. The number of researchers who can be actively involved in this area of research and the ability of researchers to pursue suggestive findings from completed studies in a timely manner are restricted by these factors.

## 2. **Gaps in the research conducted to date**

The meeting participants identified numerous gaps in the available research on non-pharmacological treatments and care practices. Many of the identified gaps pertain to subgroups of people with Alzheimer's or other dementias, in particular:

- people in various racial and ethnic groups;
- people in the early stages of Alzheimer's or other dementias;
- people with young-onset Alzheimer's or other dementias;
- people with non-Alzheimer's dementias, including vascular dementia, frontotemporal degeneration (FTD), and Lewy body dementia;
- people with Alzheimer's or dementia who also have serious co-existing medical conditions;
- people in the late stages of Alzheimer's or other dementias;
- people with intellectual disabilities who develop Alzheimer's or other dementias as they age, notably people with Down Syndrome; and
- people with Alzheimer's or other dementias who live alone and do not have a family caregiver.

The meeting participants noted that most evidence-based treatments and care practices are intended primarily for and have been delivered mainly to family caregivers. They emphasized the need for research on treatments and care practices intended primarily for and delivered mainly to the person with the condition or the person and family caregiver together, not solely the family caregiver. Several specific problems in Alzheimer's and dementia care were identified as needing more research. These problems include difficult behavioral symptoms, the current under-recognition and under-diagnosis of the conditions, and insufficient understanding about how to coordinate medical and non-medical care for people with the conditions.

One of the invited presentations described the Transitional Care Model (TCM) for Cognitively Impaired Elders, an evidence-based practice to improve care transitions from hospital to home. Research shows that older people with Alzheimer's or other dementias have twice as many transitions between hospital, home, and nursing home as other older people.<sup>99</sup> The meeting participants stressed the need for research on treatments and care practices to improve all types of care transitions for people with these conditions, including transitions to and from assisted living, nursing home, rehabilitation facility, emergency department, hospital, and home. They also noted the need for research on the role of advance planning in improving care transitions.

The meeting participants emphasized the need for research on the impact of exercise. Several RCTs have shown promising results for treatments and care practices that incorporate exercise for people with Alzheimer's or other dementias who live at home.<sup>100</sup> A 2010 National Institutes of Health (NIH) state-of-the-science conference on prevention of Alzheimer's disease and cognitive decline concluded that there is preliminary but still insufficient evidence that exercise can reduce cognitive decline in people who

already have memory problems and noted the need for further research to test this relationship.<sup>101</sup> Participants in the June 2012 meeting commented that the outcomes of future research on this issue should include not only reduction in cognitive decline but also reduction in functional decline and falls.

Despite the relatively large amount of research on treatments and care practices for family caregivers noted above, the meeting participants identified gaps in current knowledge about several caregiver-related issues. These issues include how to maintain the caregiver's health, how to help caregivers with the grieving process, and what treatments and care practices can be delivered effectively in the caregiver's workplace. They also pointed out that the most common pattern of relationships between caregivers and care recipients differs across racial and ethnic groups. The pattern of an adult child providing care for a parent with Alzheimer's or other dementias is, for example, more common in some racial and ethnic groups than in others. The meeting participants stressed that research on treatments and care practices should be designed to account for these differences so that outcomes due to the relationship of the caregiver and care recipient are not confused with outcomes due to race and ethnicity.

The meeting participants identified two other gaps in the available research: 1) insufficient information about the impact of various kinds of assistive technologies; and 2) insufficient information about the impact of in-person delivery of a treatment or care practice versus delivery by telephone or other media. The second issue is important for understanding how different delivery methods may affect people's decisions to stay in or drop out of treatment.

For people in the early stages of Alzheimer's or other dementias, the meeting participants stressed the need to identify and evaluate alternate inclusion and exclusion criteria for treatments and care practices. One meeting participant commented that when treatments are offered specifically for people in the "early stage," some individuals define themselves (or their family caregiver defines them) as "early stage" even though they are actually in a later stage of dementia. As a result, the offered treatments are unlikely to be appropriate for them.

A similar problem arises when an early-stage individual who is receiving a treatment progresses to a later stage for which the treatment is no longer appropriate. To address this problem, research is needed to identify and evaluate compassionate ways to transition the individual out of the inappropriate treatment.

Some findings from Table 1 confirm research gaps identified by the meeting participants. For example, only two of the treatments and care practices included in the table are intended specifically for people in the early stages of Alzheimer's or other dementias. None are intended specifically for people in the late stages of the conditions. Only two focus primarily on the person with the condition; twelve focus primarily on the dyad, and the remaining 30 focus primarily on the caregiver. Most are delivered in the person's or caregiver's home (23) and/or in the community (11) or a medical setting (7), and none are delivered at the caregiver's workplace.

None of the treatments and care practices shown in Table 1 are intended specifically for people with non-Alzheimer's dementias, such as vascular dementia, FTD, and Lewy body dementia, or their family caregivers. A recent review of articles published before May 2011 found no RCTs on treatments or care practices for caregivers of people with FTD.<sup>102</sup> Yet the needs of people with non-Alzheimer's dementias

and their family caregivers often differ from the needs of people with Alzheimer's disease and their caregivers.<sup>103,104,105,106</sup>

Table 1 does not show which of the treatments and care practices have been evaluated and found to have positive outcomes for people in various racial and ethnic groups. Many of the RCTs were conducted in samples that included people in particular racial and ethnic groups, but a comprehensive analysis would be required to determine which treatments and care practices have been found to have positive outcomes for exactly which groups.

Lastly, cognitive and memory training treatments are not included in Table 1, although RCTs conducted in the United States and elsewhere have found that these treatments improve cognitive functioning for some people with memory problems, mild cognitive impairment, and early Alzheimer's disease.<sup>107,108,109,110,111,112,113</sup> It is unclear whether evidence-based cognitive and memory training treatments should be made available by AAAs and other community agencies. The treatments generally have not been considered in this context. The growing need to identify treatments and care practices that work for people in the early stages of Alzheimer's or other dementias suggests, however, that it would be appropriate to consider whether community agencies should offer evidence-based cognitive and memory training treatments. Minds in Motion, a treatment presented at the June 2012 meeting and intended for people with mild cognitive impairment and early dementia, provides both cognitive training and exercise. Likewise, a recent literature review and analysis offers a detailed rationale for treatments and care practices that combine cognitive training and exercise.<sup>114</sup>

### 3. **Lack of a generally accepted classification system to organize, describe and differentiate evidence-based treatments and care practices.**

The substantial and growing body of research on evidence-based treatments and care practices is difficult to understand and describe without a system for classifying the treatments and care practices. At present, there is no generally accepted classification system. Such a system would support comprehensive analyses of what is known now and more systematic identification of research gaps than was possible in the June 2012 meeting. The meeting participants placed high priority on its development.

Developing a classification system for evidence-based treatments and care practices would involve selecting the broad categories to be used and identifying factors in each category that have been shown to be associated with treatment and care practice outcomes. Possible broad categories include: 1) the target population; 2) the types of treatments and care practices; and 3) the main problems addressed by the treatments and care practices. A brief overview of the many possible factors that could be included under these three broad categories indicates the likely scope of the task.

- The *target population* category might include three of the factors shown in Table 1 (primary targeted recipient, the person's disease or condition, and stage of dementia). It could also include many other characteristics of the person with dementia and family caregiver that have been shown to be associated with treatment and care practice outcomes, for example, their age, gender, race/ethnicity, culture, health status, co-existing medical conditions, income, living arrangements, the relationship of the person with dementia and the caregiver, and their family and other social networks.

- The *types of treatments and care practices* category could include many specific types. In 2010, an international group of Alzheimer's and dementia researchers identified 19 types of non-pharmacological treatments for people with dementia: cognitive training, behavioral interventions, cognitive stimulation, transcutaneous electrical stimulation, physical exercise, use of music, reminiscence, ADL training, massage and touch, recreation therapy, use of light, multisensory stimulation, support and psychotherapy, validation, acupuncture, transcranial magnetic stimulation, muscle relaxation, and multi-component treatments.<sup>13</sup> The group also identified five types of non-pharmacological treatments for caregivers: caregiver education, caregiver support, case management, respite care, and multi-component treatments. Although extensive, this list does not include other types of treatments and care practices discussed by participants in the June 2012 meeting, for example, education, peer support, and mentoring for the person with dementia and skills training for the family caregiver.
- The *main problems addressed by the treatments and care practices* category could include many specific problems. Examples are lack of information about dementia and dementia care; lack of pleasant and meaningful activities, and reduced quality of life for the person; lack of support for the caregiver; and feelings of depression and anxiety for the person and the caregiver. This category could instead be labeled *main outcomes to be achieved by the treatments and care practices*, and the problems could be restated as outcomes, for example, increased knowledge about dementia and dementia care for the person and family caregiver, increased pleasant and meaningful activities for the person, and increased support for the caregiver.
- In 2011, a team of U.S. researchers created a classification system for treatments and care practices that is based on family caregiver skills and related outcomes for the caregiver and the care recipient.<sup>15</sup> The classification system is not specific to Alzheimer's or dementia, but its categories and subcategories may be helpful in thinking about a dementia-specific classification system. The first broad category, family caregiver skills, includes clinical skills and knowledge, psychological skills and resources, support seeking skills, and quantity of caregiving. The second broad category, outcomes for caregivers, includes 40 subcategories, such as depression, anxiety, and beliefs about caregiving. The third broad category, outcomes for the care recipient, includes 27 subcategories, such as coping, quality of life, depression, and family and social functioning.

The large number of factors that have been found to be associated with treatment and care practice outcomes would make it difficult to develop the classification system. Agreement would have to be reached on mutually exclusive definitions for each of the selected characteristics of the person with dementia and caregiver, each type of treatment and care practice, and each identified problem or outcome. Participants at the June 2012 meeting noted other decisions that would have to be made in developing the classification system:

- how to incorporate methodological information about the RCTs, for example, sample size, randomization procedures, and standards of statistical significance; and
- whether and, if so, how to incorporate information about negative outcomes, which is frequently useful for refining treatments and care practices.

The most difficult decision to be made in developing the classification system might be how to categorize multi-component treatments and care practices. Many of the treatments and care practices shown in Table 1 combine several treatments and care practices. RCT outcomes for multi-component treatments and care practices are usually reported for the combined components, and it is not possible to determine whether the outcomes resulted from one or more of the components or the combined components. It is unclear whether these treatments and care practices can and should be categorized according to their components or conversely, as a separate category of multi-component treatments and care practices and how that decision will affect the usefulness of the classification system.

Given the difficulty of developing the needed classification system, participants in the June 2012 meeting suggested the system should be created by researchers and clinicians who have been involved in the implementation and evaluation of existing evidence-based treatments and care practices. Community agency administrators and community service providers who have been involved in implementing the treatments and care practices could also contribute valuable perspectives.

Once a classification system is developed and existing treatments and care practices are entered into it, a systematic identification of research gaps should be possible. It should also be possible to determine whether evidence-based treatments and care practices developed in other countries or for other care settings in the U.S. will be useful in filling some of the gaps.

In addition to its value for understanding and explaining what is known now and identifying research gaps, the classification system might eventually provide a basis for comparing treatments and care practices. In the June 2012 meeting, discussion about the need for a classification system was stimulated by a question raised in the meeting about whether it is time for head-to-head comparisons of the existing treatments and care practices to determine which ones are best. The meeting participants strongly rejected this idea. They acknowledged that some treatments and care practices are probably better than others. They pointed out, however, that different types of treatments and care practices are likely to be effective for individuals and family caregivers with particular characteristics, problems, and caregiving situations. For this reason, an array of treatments and care practices will always be needed. For the same reason, head-to-head comparisons are only appropriate for treatments and care practices provided for similar individuals and families with similar problems and caregiving situations. The current lack of a generally accepted classification system that incorporates these factors means it is not possible to make valid comparisons at present, but development of such a system might allow for valid comparisons in the future. The meeting participants also noted that availability of a generally accepted classification system might eventually allow for the creation and use of quality measures to evaluate whether appropriate treatments and care practices have been provided.

Lastly, a generally accepted classification system might provide a basis for more effective communication about evidence-based treatments and care practices. As noted earlier, the existing treatments and care practices are not well known outside the community of researchers, clinicians, and community agency administrators and service providers who developed, implemented, and evaluated them and the public and private organizations that funded this work. Expanding awareness and availability of these treatments and care practices will require better ways of explaining them to people

who make decisions about funding, providing, and using them. The language of a classification system is unlikely to be understood or meaningful to most of these people. Moreover, it may not be possible to incorporate findings from translation studies about the real-world feasibility and effectiveness of the treatments and care practices. On the other hand, a generally accepted categorization of the different types of evidence-based treatments and care practices and the characteristics and problems of people who are likely to benefit from them would provide concepts and information that could be adapted, with simplified language, to improve communication and expand awareness about them.

#### 4. **Failure to evaluate impacts on people with Alzheimer’s or other dementias in research on non-pharmacological treatments and care practices for older people in general**

People with Alzheimer’s or other dementias have been explicitly excluded from some studies of non-pharmacological treatments and care practices intended for older people in general. In other studies of such treatments and care practices, the exclusion criteria are unclear, so it is not possible to figure out how many, if any, people with the conditions were included. A 2012 analysis of articles about research published in the *Journal of the American Geriatrics Society* in 2008 and 2009 found that 29% of the articles described research that explicitly excluded people with cognitive impairment or dementia. Another 53% provided insufficient information to determine whether people with the conditions were excluded.<sup>116</sup> More than half of the articles about research that explicitly excluded people with cognitive impairment and dementia gave no reason for the exclusion. Moreover, many of the articles did not provide any information about how “cognitive impairment” and “dementia” were recognized or measured.

Clearly, not all of the articles included in the analysis described above were about research on non-pharmacological treatments and care practices, but some undoubtedly were. Exclusion of people with Alzheimer’s or other dementias from such research and lack of clear information about how many people with the conditions were in the study samples result in lost opportunities to determine whether, and if so how well, the treatments and care practices work for these people.

The Care Transitions Intervention (CTI) and Guided Care are two non-pharmacological treatments and care practices intended for older people in general that might be expected to result in positive outcomes for people with Alzheimer’s or other dementias. CTI is an evidence-based care practice in which a trained coach works to improve transitions from hospital to home for older people with serious medical conditions. Two RCTs of CTI excluded individuals if dementia was documented in their medical record.<sup>117,118</sup> People who answered less than three questions correctly on a 4-item cognitive screening test were also excluded unless they had a proxy to provide informed consent. The articles that report the RCT findings do not say how many people with either undocumented dementia or cognitive impairment and an available proxy were included in the RCT samples or how CTI worked for them specifically.

Guided Care is an evidence-based care practice in which registered nurses are integrated into primary care physician offices to improve the quality of care for older people with multiple chronic conditions. The RCT on Guided Care excluded people who failed a brief cognitive screen and did not have a close family member or legal guardian to act as a proxy.<sup>119</sup> One article that reports findings from the RCT says that people with Alzheimer’s or other dementias made up about 4% of the RCT sample.<sup>120</sup> The impact of

Guided Care on those people has not been reported, however, and it is not clear whether a 4% subgroup is sufficient to support valid analyses.

Tailored Caregiver Assessment and Referral (T-CARE<sup>®</sup>) is a third non-pharmacological care practice intended for family caregivers of older people in general that might be expected to result in positive outcomes for caregivers of people with Alzheimer's or other dementias. The original RCT for T-CARE<sup>®</sup> was conducted in a sample of family caregivers that included, but was not limited to, caregivers of people with memory problems or suspected or diagnosed Alzheimer's or other dementias.<sup>121</sup> The article that reports findings from that RCT notes the proportion of family caregivers who were taking care of people with the conditions, but it does not report outcomes for them specifically. However, another RCT was conducted in a sample that included only caregivers of people with memory problems or suspected or diagnosed Alzheimer's or other dementias and found positive outcomes for those caregivers.

In some circumstances, it is understandable that people with Alzheimer's or other dementias are excluded from research on treatments and care practices for older people in general. For example, it makes sense to exclude them when the research is about a treatment intended to reduce new cases of dementia, but such situations are probably infrequent. Going forward, meeting participants said that people with Alzheimer's or other dementias should be included as often as possible in research on treatments and care practices intended for older people in general. Alzheimer's and other dementias should be identified in the study samples, and study findings should be analyzed to determine the effects of the treatments and care practices for these people specifically.

## 5. **Lack of support for studies using research designs other than RCTs**

As noted earlier, the RCT is the gold standard research design for rigorous scientific evaluation. Some participants at the June 2012 meeting commented that RCTs should not be the only acceptable research design to evaluate non-pharmacological treatments and care practices. The meeting participants did not identify research topics that would require evaluation using a different research design. Several highly regarded Alzheimer's and dementia care practices that were developed with AoA funding and have been widely replicated were evaluated using less rigorous research. One example is El Portal, a care practice intended to increase the capacity of ethnic communities to provide culturally competent outreach and services for people with Alzheimer's or other dementias.<sup>122,123</sup> It is hard to imagine how the important community-level components of El Portal could have been implemented if randomization of individuals had been required for a RCT.

Some of the research gaps identified by the meeting participants may reflect difficulties in conducting a RCT on a particular topic. One example might be treatments and care practices for people in the late stages of Alzheimer's or other dementias. A 2010 review of published and unpublished English language studies of treatments and care practices to improve end-of-life care for people with dementia found no RCTs for people living at home.<sup>124</sup> Given the importance of finding ways to improve care for people with late-stage Alzheimer's or other dementias, it may be useful to determine whether ethical and/or other concerns about randomizing late-stage people to the treatment group or the control (non-treatment) group is a major barrier to the development and evaluation of effective late-stage and end-of-life treatments and care practices.

## **TRANSLATION STUDIES TO TEST EVIDENCE-BASED, NON-PHARMACOLOGICAL TREATMENTS AND CARE PRACTICES IN COMMUNITY SETTINGS**

As noted at the beginning of this white paper, translation studies are intended to determine whether evidence-based treatments and care practices can be implemented successfully and result in the same positive outcomes when they are provided outside the highly structured context of a RCT. While RCTs are often said to result in findings about the *efficacy* of a treatment or care practice, translation studies are said to result in findings about its *effectiveness*.

Translation studies can test a wide array of factors that may affect the real-world feasibility and effectiveness of an evidence-based treatment or care practice. A translation study could, for example, test whether an evidence-based treatment or care practice works for people with Alzheimer's or other dementias who also have physical or mental health conditions and therefore, may have been excluded from the RCT sample. Likewise, a translation project could test whether the treatment or care practice can be delivered effectively by AAA staff or other community service providers rather than the research staff who delivered it in the RCT.

The generally accepted model for moving from an idea or hypothesis about a treatment or care practice to wide availability of the treatment or care practice in the community usually starts with design, initial testing, refinement, and then a RCT to evaluate efficacy. In this model, one or more translation studies come next. If these studies show the treatment or care practice is feasible for delivery in the community and has outcomes similar to the positive outcomes from the RCT, the next step is to make it widely available. Participants in the June 2012 meeting noted, however, that findings from translation studies often suggest changes that could be made in the evidence-based treatment or care practice to improve its outcomes. Several of the meeting participants said they have made such changes in treatments and care practices they developed. Thus, the linear model for moving from an idea or hypothesis to development, pilot testing, RCT, translation studies, and community availability may not always apply. Implications of a non-linear model that incorporates findings from translation studies into the original treatment or care practice are discussed later in this section.

### **Translation studies conducted since 2002**

Since 2002, translation studies have been conducted to test the effectiveness of ten of the evidence-based treatments and care practices included in Table 1. Table 2 shows the ten treatments and care practices, the states in which the translation studies have been or are being conducted, the funding source, and the year or years in which funding began. Table 2 includes only translation studies intended exclusively for people with Alzheimer's or other dementias and/or their family caregivers. Data from the table indicate that 50 such studies have been funded since 2002. These translation studies have been or are being conducted in 24 states, including eight states with one translation study and 16 states with two or more translation studies.



**Table 2: Translation Studies of Evidence-Based Non-Pharmacological Treatments and Care Practices for People with Alzheimer’s or Other Dementias and Their Family Caregivers, by State, Funding Source, and Year Funding Began, United States, 2002-2012.**

Treatments and Care Practices*	State	Funding Source**	Year Funding Began
BRI Care Counseling	Georgia	AoA/ADSSP	2010
BRI Care Counseling	Tennessee	AoA/ADSSP	2009
Coping with Caregiving	Arizona	AoA/ADSSP	2008, 2009
Coping with Caregiving	Nevada	AoA/ADSSP	2009
Coping with Caregiving	Tennessee	AoA/ADSSP	2004
New York University Caregiver Intervention (NYUCI)	California	AoA/ADSSP	2009
New York University Caregiver Intervention (NYUCI)	Florida	AoA/ADSSP	2010
New York University Caregiver Intervention (NYUCI)	Georgia	AoA/ADSSP	2009
New York University Caregiver Intervention (NYUCI)	Minnesota	AoA/ADSSP and AoA/SI	2007, 2008, 2009, 2012
New York University Caregiver Intervention (NYUCI)	Nevada	RCI and J&J	2009
New York University Caregiver Intervention (NYUCI)	New York	RCI and J&J	2007
New York University Caregiver Intervention (NYUCI)	New York	AoA/SI	2011
New York University Caregiver Intervention (NYUCI)	Utah	AoA/ADSSP	2010
New York University Caregiver Intervention (NYUCI)	Vermont	RCI and J&J	2007
New York University Caregiver Intervention (NYUCI)	Wisconsin	AoA/ADSSP	2010
Partners in Dementia Care (PDC)	Ohio	AoA/SI	2011
Reducing Disability in Alzheimer’s Disease (RDAD)	Ohio	AoA/ADSSP	2008, 2010
Reducing Disability in Alzheimer’s Disease (RDAD)	Oregon	NIA	2012
Reducing Disability in Alzheimer’s Disease (RDAD)	Washington	NIA	2012
Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II)	Alabama	AoA/ADSSP	2004
Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II)	Florida	AoA/ADSSP	2008
Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II)	Georgia	AoA/ADSSP	2008, 2010
Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II)	Hawaii	RCI and J&J	2012
Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II)	Nevada	RCI and J&J	2012
Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II)	New York	RCI and J&J	2012
Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II)	North Carolina	AoA/ADSSP	2008, 2010
Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II)	Texas	RCI and J&J	2007, 2012
Savvy Caregiver	California	AoA/ADSSP	2007, 2008
Savvy Caregiver	Colorado	AoA/ADSSP	2002, 2005
Savvy Caregiver	Maine	AoA/ADSSP	2008, 2010

(continued)

**Table 2: Translation Studies of Evidence-Based Non-Pharmacological Treatments and Care Practices for People with Alzheimer’s or Other Dementias and Their Family Caregivers, by State, Funding Source, and Year Funding Began, United States, 2002-2012 (continued).**

Treatments and Care Practices*	State	Funding Source**	Year Funding Began
Savvy Caregiver	Michigan	AoA/ADSSP	2008, 2009 2010
Savvy Caregiver	New Mexico	AoA/ADSSP	2010
Skills <sub>2</sub> Care (formerly Environmental Skill Building)	Florida	RCI and J&J	2009
Skills <sub>2</sub> Care (formerly Environmental Skill Building)	New Jersey	AoA/ADSSP	2007
Skills <sub>2</sub> Care (formerly Environmental Skill Building)	New Jersey	RCI and J&J	2007
STAR Caregiver (STAR-C)	Oregon	AoA/ADSSP	2009
Tailored Activities Program	Kentucky	AoA/ADSSP	2010

\* References for each of the treatments and care practices are provided in Table 1.

\*\* AoA/ADSSP is the congressionally mandated Alzheimer’s Disease Supportive Services Program administered by AoA. RCI is the Rosalynn Carter Institute for Caregiving.

J&J is Johnson and Johnson, a New Jersey-based corporation.

AoA/SI is the 2011 Administration on Aging grant program intended to create “sustainable, dementia capable service systems for persons with dementia and their family caregivers.”<sup>125</sup>

The U.S. Administration on Aging (AoA) has funded the majority of the translation studies shown in Table 2, primarily through the congressionally mandated Alzheimer’s Disease Supportive Services Program (ADSSP). The Rosalynn Carter Institute for Caregiving, with support from Johnson & Johnson, has funded many others.

From 2002 through 2005, three states received ADSSP grants for translation studies. In 2007, the grant announcement for ADSSP noted AoA’s expectation that states would “review and use findings from research on evidence-based service models and techniques to support people with Alzheimer’s disease and their family caregivers” as they developed their ADSSP grant proposals.<sup>126</sup> Beginning in 2008, AoA created a separate category of ADSSP grants for studies to translate evidence-based treatments and care practices to the community. From 2007 through 2011, 17 states received ADSSP grants for 31 translation studies.

In 2007, the Rosalynn Carter Institute for Caregiving (RCI) and Johnson & Johnson (J&J) began funding translation studies to test evidence-based, non-pharmacological treatments and care practices for various groups. From 2007-2012, RCI and J&J funded 11 studies in eight states to test evidence-based treatments and care practices for people with Alzheimer’s or other dementias and their family caregivers.

In 2011 and 2012, two federal agencies used new funding mechanisms to support translation of evidence-based Alzheimer’s and dementia treatments and care practices to community settings. In 2011, AoA provided funding for four states through a new grant program intended to create “sustainable, dementia capable service systems for persons with dementia and their family caregivers.”<sup>125</sup> As part of creating dementia capable service systems, the four states (Georgia, Minnesota, New York, and Ohio) will implement or expand implementation of one of the evidence-based treatments and care practices. As noted earlier, in 2012, the University of Washington received funding for a translation study on Reducing Disability in

Alzheimer's Disease (RDAD) through the joint NIA/AoA research grant program, *Translational Research to Help Older Adults Maintain their Health and Independence in the Community*.<sup>90</sup>

In addition to the 50 translation studies shown in Table 2, the U.S. Department of Veterans Affairs (VA) provided funding in 2007 for translation studies in 24 VA medical centers in 15 states. These studies tested the effectiveness of REACH II for family caregivers of older veterans with diagnosed Alzheimer's disease or dementia who were enrolled in VA Home-Based Primary Care (HBPC) programs.<sup>95</sup>

## **Observations from the June 2012 meeting and literature review**

### **1. The substantial number of Alzheimer's and dementia translation studies that have been funded since 2002 is surprising and impressive.**

The number of translation studies funded by public and private sources since 2002 has not been previously reported. Sustained funding through ADSSP and RCI and J&J is responsible for most of these studies. Yet recent grants from federal agencies using new funding mechanisms suggest a growing awareness of the positive outcomes from some of the evidence-based treatments and care practices and the importance of further testing to increase knowledge about their feasibility and effectiveness in community settings. On the community side, the substantial number of completed and ongoing translation studies indicates awareness in some community agencies of the need for programs to help people with Alzheimer's or other dementias and their family caregivers. It also indicates that many community agencies are willing to try evidence-based treatments and care practices.

### **2. Some information about findings from translation studies has been published.**

As of mid-2012, at least 11 articles have been published about translation studies that have tested evidence-based treatments and care practices for people with Alzheimer's or other dementias and their family caregivers. The articles provide information about the translation process and the community agencies that participated in studies to test the following treatments and care practices.

- Savvy Caregiver, the current name for the Minnesota Family Workshop (MFW) evidence-based treatment: five articles discuss the implementation and effectiveness of Savvy Caregiver as delivered by Area Agencies on Aging (AAAs) and Alzheimer's Association Chapters in Maine, Minnesota, Colorado, Alaska and Mississippi.<sup>127,128,129,130,131</sup>
- REACH II: two articles discuss the implementation and effectiveness of REACH II as delivered by trained volunteers and community agency staff through a partnership between the Central Texas AAA and Scott and White Healthcare, a clinical partner of the Texas A&M University Health Science Center.<sup>96,97</sup>
- REACH OUT, a translation version of REACH II: one article discusses the implementation and effectiveness of REACH OUT as delivered by AAAs in Alabama.<sup>94</sup>
- REACH VA, a translation version of REACH II: one article discusses the implementation and effectiveness of REACH VA as delivered by Home-Based Primary Care (HBPC) staff in 24 VA medical centers in 15 states.<sup>95</sup>

- Skills<sub>2</sub>Care: one article discusses the implementation of Skills<sub>2</sub>Care as delivered by occupational therapists affiliated with a private home care organization that provides house calls for older adults in five mid-Atlantic states using Medicare Part B funding.<sup>91</sup>
- RDAD and STAR-Caregivers (STAR-C): one article discusses the implementation and effectiveness of RDAD and STAR-C as delivered by AAAs and Alzheimer’s Association Chapters in Oregon and Ohio.<sup>132</sup>

### 3. **Many of the translation studies have tested modifications to the original evidence-based treatment or care practice.**

As noted above, the REACH OUT and REACH VA studies tested translation versions of REACH II. In addition, one project tested a translation version of Savvy Caregiver.

- To accommodate VA concerns about the length of the assessment instrument used to identify the difficult aspects of caregiving for each family caregiver, REACH VA eliminated 30 of the 51 questions from the original REACH II assessment instrument. REACH VA also added a few questions to obtain information about topics important to the VA, such as the veteran’s non-VA health care providers.<sup>95</sup>
- To accommodate concerns of the Alabama AAAs about the feasibility of implementing various components of REACH II, REACH OUT eliminated 30 of the 51 questions in the original REACH II assessment instrument, reduced the number of in-home visits from nine to four, and reduced the duration of the program from six months to four months.<sup>94</sup>
- To accommodate the long travel times of rural family caregivers, the Savvy Caregiver translation study implemented by Colorado AAAs and the Colorado Alzheimer’s Association Chapter tested three modifications to the duration of the program. Specifically, the project staff delivered Savvy Caregiver in one-week, 2-week, and 3-week periods instead of the original 6-week period.<sup>130</sup>

As described in the published articles, the modifications and their implications for the feasibility and effectiveness of the treatments and care practices were carefully considered before implementation and reviewed in detail at the end of the study.

Participants in the June 2012 meeting discussed modifications that are being tested or have been proposed for other treatments and care practices presented at the meeting. Several of the ADSSP-funded NYUCI translation studies are testing a modification to the enrollment criteria for the original NYUCI, which included only spouse caregivers. The translation studies found that in some racial and ethnic minority communities, most people with Alzheimer’s or other dementias had an adult child caregiver rather than a spouse caregiver. The studies are now testing expanded enrollment criteria that include adult child caregivers.

For the Collaborative Care Model for Alzheimer’s Disease and Related Dementias,<sup>66</sup> a modification was proposed at the meeting by the original researcher but has not yet been tested. The proposed modification

would provide most parts of the treatment in the person's home as opposed to medical clinics where the treatment was provided in the original program.

## **Issues and Concerns from the June 2012 Meeting**

The substantial number of completed and ongoing translation studies creates a rich body of implementation experience and knowledge about the ten evidence-based treatments and care practices in particular and the translation process in general. All but four of the translation studies were funded in the past six years. For that reason, much of what has been learned has not yet been published or even fully analyzed. Participants in the June 2012 meeting identified six important concerns about the current status and future prospects for translation work in this area.

### **1. Lack of sufficient funding for translation studies**

The meeting participants noted that despite the substantial number of translation studies funded since 2002, additional funding is needed to test the ten treatments and care practices shown in Table 2 in larger and more diverse populations and different types of community agencies and settings. Moreover, many of the evidence-based treatments and care practices shown in Table 1 have not been tested in any translation studies to date and should be.

Some federal agencies and private organizations prefer to fund original research rather than studies that translate existing research to practice. The amount and consistency of funding provided by the ADSSP program and RCI and J&J have been valuable and noteworthy. Future funding from these and other public and private sources could support testing of additional evidence-based treatments and care practices. Such funding could also expand the number and diversity of people with Alzheimer's or other dementias and family caregivers for whom various treatments and care practices have been tested.

### **2. Lack of sufficient funding for analysis of findings and experience from translation studies**

As the number of translation studies increases, the need for analysis to distill important findings and clinical and operational experience from the studies also increases. Each funding source requires a final report on findings and lessons learned. After a translation study ends, however, the researchers and administrators who developed and directed the study and the community agency staff and other service providers who delivered the treatment or care practice usually return to their previous work or move on to new projects. As a result, the study findings and experiences may not be submitted for publication, and information that would be helpful in planning future efforts to expand effective treatments and care practices to more communities will not be available to most people who need that information.

As shown in Table 2, multiple translation studies have tested or are testing the same treatment or care practice. Since 2002, studies to test the NYUCI have been conducted in ten states. Studies to test REACH II have been conducted in eight states and 24 VA medical centers, and studies to test Savvy Caregiver have been conducted in five states. As these translation studies are completed, there is an opportunity to analyze the findings and experiences from multiple studies of the same treatment or care practice. Such an analysis would include larger numbers and more diverse populations of people with

Alzheimer's or other dementias and family caregivers and more and different types of community agencies and service providers. As a result, the analysis would add greatly to current knowledge about the characteristics of people with these conditions who are more or less likely to benefit from the treatment or care practice and the community agencies and service providers that are more or less able to deliver it effectively. The analysis could also document implementation challenges confronted by different studies and how they responded to the challenges.

Researchers, project administrators, and community agency staff members that implement the same evidence-based treatments and care practices often exchange this kind of information in meetings organized by the funding source, usually on an annual basis, and sometimes in group conference calls. The translation studies end at very different times, however, and it would require sustained effort, methodical procedures, and resources that are not available in most existing translation study budgets to gather and analyze the final results and other relevant information from all the studies. It is unclear which, if any, federal agencies or private organizations would pay for this work, despite its importance.

### **3. Difficulty recruiting people with Alzheimer's or other dementias and family caregivers to participate in some translation studies**

Some translation studies have had considerable difficulty recruiting people with Alzheimer's or other dementias and family caregivers who meet the study enrollment criteria. Participants in the June 2012 meeting commented that many people who have (or their family member has) these conditions, are reluctant to participate in research because of stigma associated with the conditions. The meeting participants also noted that some people with the conditions have not been diagnosed, and they and their family caregivers may not be aware they have Alzheimer's or dementia. Still others may not understand the research or its potential to help them.

Some translation studies use enrollment criteria that exactly match the enrollment criteria in the original research on the treatment or care practice they are testing. Other translation studies use more restrictive enrollment criteria to learn about the effectiveness of a treatment or care practice for a more restricted target population, for example, a racial or ethnic group or people in a particular stage of dementia.

For a translation study, failure to recruit a sufficient number of people with Alzheimer's or other dementias or family caregivers who meet the study enrollment criteria is discouraging and may create pressure to expand the enrollment criteria. On the one hand, expanding the enrollment criteria could result in higher enrollment and, therefore, more credible findings about the effectiveness of the treatment or care practice. On the other hand, expanding the enrollment criteria often means losing the opportunity to find out whether the treatment or care practice is effective for the population targeted in the study.

Regardless of whether a decision is made to expand the enrollment criteria for a translation study, information about the reasons for recruitment difficulties would be useful for future research and translation studies. Recruitment difficulties could mean the treatment or care practice is not being presented effectively to people who might use it. Alternatively, it could mean there are not enough such people in the community where it is being offered or that some aspect of the treatment or care practice is not acceptable to them. If the recruitment difficulties are resolved and the treatment or care practice is

found to be effective, information about the reasons for early recruitment difficulties could be helpful in designing future marketing efforts, gauging how many people might use the treatment or care practice in a given type of community, and considering modifications to make the treatment or care practice more acceptable to such people.

4. **Difficulty finding community service providers who can deliver the evidence-based treatments and care practices effectively**

Some translation studies have had difficulty hiring or contracting with community service providers who are able to deliver the treatment or care practice effectively. Several participants in the June 2012 meeting said they had difficulty finding community service providers with sufficient education and experience to deliver the treatment or care practice effectively. These meeting participants acknowledged that the obvious response to this problem is to increase the amount of training for the service providers. They pointed out, however, that increasing the amount of training also increases the length of time before delivery of the treatment or care practice can begin and its cost.

Other meeting participants who had experienced difficulty finding community service providers who could deliver their treatment or care practice effectively said the main problem was finding caring individuals with the interpersonal skills needed to gain trust and work well with people with Alzheimer's or other dementias and family caregivers. These meeting participants said that if they found caring individuals, they could easily train the individuals to deliver the treatment or care practice effectively.

At least one of the translation studies presented at the June 2012 meeting developed a list of competencies for community agency staff and other service providers who deliver the treatment or care practice being tested in the project. Other translation studies have increased training and offered it through different media.

Although challenging for a translation study, difficulties in finding community service providers who can deliver a treatment or care practice effectively could result in useful information for future expansion of the treatment or care practice. The extent to which the education, experience, and interpersonal skills needed by community service providers differ for different evidence-based treatments and care practices is unclear. Analysis of the experience of translation studies that have tested or are testing different treatments and care practices could help to clarify this issue.

5. **Whether, and if so when, it is acceptable to incorporate lessons learned from a translation study into an evidence-based treatment or care practice without conducting a new RCT**

As noted earlier, many of the translation studies conducted to date have tested or are testing modifications to the original treatment or care practice. On the one hand, it is generally accepted that translation studies should maintain fidelity to the original treatment or care practice in order to achieve the positive outcomes shown in the original research that established its efficacy. On the other hand, participants in the June 2012 meeting noted that lessons learned from translation studies often improve the treatment or care practice. They questioned whether it is reasonable to maintain fidelity to the

original treatment or care practice when experience in a translation study identifies changes that seem to improve the treatment or care practice. They also pointed out that conducting a new RCT to evaluate every change is prohibitively costly and time-consuming.

The meeting participants stressed the need for further discussion about this issue. Ideally, that discussion would result in consensus about the circumstances in which it is acceptable to incorporate changes based on lessons learned in a translation study without a new RCT, and conversely, when it is necessary to conduct the new RCT.

## 6. **Role of the original researcher(s) and others in translation studies**

Some translation studies have been led by the researcher(s) who conducted the original study or studies that established the efficacy of the treatment or care practice. Other translation studies have been led at first by the original researcher(s) but then turned over to others for ongoing management and oversight. Likewise, some original researchers have provided training throughout the translation study for the community service providers who deliver the treatment or care practice. Other original researchers have not provided training for translation studies at all or have turned training over to someone else in the course of the studies. Additionally, some original researchers have developed or participated in the development of a train-the-trainer program or a web-based training program for community service providers.

Participants in the June 2012 meeting pointed out that even though the original researcher(s) may be in demand to lead translation studies and train the community service providers, the original researcher(s) may not be the best person(s) to perform these functions. Moreover, as the number of translation studies for a particular treatment or care practice increases, the original researcher(s) may be unable to provide the necessary leadership and training.

In addition to leadership and training, the meeting participants identified other functions associated with translation studies that could be performed by the original researcher(s) or someone else. They noted that changes that affect the viability of the project, for example, turnover in community agency leadership and community service providers, frequently require decisions that could be made by the original researcher(s) or someone else. Other such functions include updating manuals and websites and monitoring implementation of the treatment or care practice.

In completed and ongoing Alzheimer's and dementia-related translation studies, practice has varied widely with respect to who performs each of these functions. The variation undoubtedly reflects preferences of the original researcher(s). It may also reflect lack of awareness among original researchers and translation study staff about different ways other original researchers and translation studies are handling the functions. The meeting participants suggested that a forum should be created for sharing this information. Available information about how original researchers and studies are handling these functions in other areas, for example, translation studies conducted in AoA and U.S. Centers for Disease Control and Prevention (CDC) Healthy Aging programs, would be helpful in this context.



## EXPANSION AND SUSTAINABILITY

Participants at the June 2012 meeting identified and discussed five interrelated factors that are critical for the expansion and long-term sustainability of evidence-based non-pharmacological treatments and care practices to help people with Alzheimer's or other dementias and their family caregivers:

- Availability of financial support,
- Demonstrated efficacy, effectiveness, and cost effectiveness,
- Development and use of easily understood concepts and terms to describe and differentiate the treatments and care practices for potential providers, people with Alzheimer's or other dementias, and family caregivers,
- Evaluation of alternate ways to connect people to the right treatments and care practices at the right time for them, and
- Ongoing maintenance of updated information about evidence-based treatments and care practices, translation study findings, and sources of financial support

### Availability of financial support

Participants in the June 2012 meeting reported that some public and private programs and organizations are providing financial support for three of the evidence-based treatments and care practices presented at the meeting. Individuals are paying out-of-pocket to use two of them:

- Medicare is reimbursing three home health agencies for delivery of Skills<sub>2</sub>Care (through Medicare Part A). Medicare is also reimbursing two private agencies that offer occupational therapy services and Jefferson Elder Care's comprehensive dementia care program for delivery of Skills<sub>2</sub>Care (through Medicare Part B).
- Some individuals are paying out-of-pocket for Skills<sub>2</sub>Care delivered by Jefferson Elder Care in Philadelphia.
- The National Family Caregiver Support Program (NFCSP) is supporting the delivery of Skills<sub>2</sub>Care in five AAAs.
- Two private health insurance companies, Aetna and Independence Blue Cross Blue Shield, are paying for TCM for Cognitively Impaired Elders for specified enrollees.
- The University of Pennsylvania Health System is providing TCM for Cognitively Impaired Elders for its members.
- Some individuals are paying out-of-pocket for Minds in Motion, and philanthropic support has been obtained to provide scholarships for individuals who cannot afford the out-of-pocket payment.

In addition to sources of financial support reported at the June 2012 meeting, information is available about sources of financial support for several other treatments and care practices. The VA is offering training for its staff to deliver the REACH VA Dementia Program as part of VA caregiver services authorized by

Congress in 2010.<sup>133</sup> Trained VA staff members can deliver the program to family caregivers of veterans with Alzheimer's or other dementias who are receiving VA Home-Based Primary Care (HBPC) or other services in VA medical centers and outpatient clinics across the country.

Trained staff in AAAs in Georgia and Washington State are delivering T-CARE<sup>®</sup> to family caregivers of people with Alzheimer's or other dementias. Several Alzheimer's Association chapters in California are delivering Savvy Caregiver as one of their ongoing programs, and several assisted living companies in California have paid Alzheimer's Association chapters for providing Savvy Caregiver to prospective residents and their families. Savvy Caregiver has also been provided on a tuition basis in a few locations in California. In Minnesota, training about NYUCI will be provided for staff in the state's Health Care Homes (Minnesota's term for medical homes) in connection with the legislatively mandated Medical Home Learning Collaborative.

Some of these examples involve direct payment, such as Medicare reimbursement for a covered benefit or out-of-pocket payment by an individual. Other examples involve situations in which the treatment or care practice is *embedded in* the ongoing services of an organization or agency. In these situations, there is usually no direct payment, and delivery of the treatment or care practice may seem to be cost-free. That is not the case, however, since the program or organization is using its resources to support delivery of the treatment or care practice, sometimes instead of other services. The VA training and support for delivery of REACH VA and the NFCSP support for AAA delivery of Skills<sub>2</sub>Care are situations of this kind.

The examples of financial support described above are encouraging and suggest sources of support that might be available for other treatments and care practices. Still, participants in the June 2012 meeting pointed out that it took a long time to obtain the current financial support, and maintaining that support often requires significant ongoing efforts by the original researcher(s) and others. In addition, there are substantial restrictions on eligibility for some of the treatments and care practices. For example, Medicare Part A reimbursement for Skills<sub>2</sub>Care is only available to a family caregiver if the care recipient is eligible for Medicare-covered occupational therapy services.

The 2010 health reform law (Public Law 111.148) authorized many programs that could provide opportunities for expansion and sustainability of evidence-based treatments and care practices. One program that could provide financial support for treatments and care practices for family caregivers is the Geriatric Education and Training Awards program authorized by Section 5305 of the health reform law. This program mandates support for Geriatric Education Centers (GECs) to offer at least two courses annually for family caregivers and direct care workers that include training on how to manage behavioral and psychological symptoms of dementia and how to communicate effectively with an individual with dementia. Many of the evidence-based treatments and care practices discussed in this white paper could be used by GECs for this purpose. The Health Resources and Services Administration (HRSA) has already made payments to more than 40 GECs through the program.<sup>134</sup> GECs could decide to deliver evidence-based treatments and care practices with this or future program funding.

## Demonstration of efficacy, effectiveness, and cost effectiveness

As defined in this white paper, the efficacy of evidence-based treatments and care practices has been demonstrated in findings from one or more published RCTs. Effectiveness has been demonstrated in published findings from translation studies that tested some of the treatments and care practices. Researchers, program administrators, and community service providers who participated in translation studies of other treatments and care practices should be encouraged to publish their findings.

Limited cost effectiveness information is available for a few of the evidence-based treatments and care practices:

- An analysis of REACH II data from the Memphis site found a statistically significant difference between treatment and control group caregivers in the number of hours per day they spent in caregiving. Caregivers who received the REACH II treatment gained one extra hour per day that was not spent in caregiving, and the estimated cost of this extra hour was \$5 a day.<sup>58</sup>
- An analysis of the Tailored Activities Program (TAP) found a statistically significant difference between treatment and control group caregivers in the number of hours per day they spent in caregiving and the number of hours they felt they were “on duty” to care for their relative with Alzheimer’s or other dementia. Caregivers who participated in the TAP treatment gained one extra hour per day that was not spent in caregiving at an estimated cost of \$2.37 a day. The estimated cost of the extra hour per day that caregivers felt they were not “on duty” was \$1.10 a day.<sup>52</sup>

Research findings showing that evidence-based treatments and care practices are cost effective would be expected to increase the willingness of public and private programs and organizations to provide financial support for them. Participants in the June 2012 meeting observed that different programs and organizations are interested in costs and cost effectiveness information about different kinds of services. Medicare and private health insurance companies are generally interested in findings that reflect reduction in the use of hospital, emergency department (ED), and other medical care services because they pay for those services. Thus far, no evidence-based Alzheimer’s or dementia treatment or care practice has shown reduced use of these kinds of services for people in the treatment group as a whole. Findings from the Cleveland Alzheimer’s Managed Care Demonstration, however, show statistically significant reductions in hospital and ED use for a subgroup of people in the treatment group, specifically, those whose cognitive impairment worsened during the one-year study.<sup>65</sup>

In contrast to Medicare and private health insurance companies, Medicaid program administrators are generally interested in findings that reflect reduction in long-term nursing home stays. NYUCI findings show a statistically significant delay of 557 days to nursing home placement for the treatment group compared with the control group.<sup>22</sup>

The meeting participants said programs and organizations that might provide financial support for evidence-based treatments and care practices often expect short-term results, including cost reductions or savings, that are difficult to achieve for people with Alzheimer’s or other dementias. They also said that the services of greatest interest to potential funders change over time. Recently, interest has focused on 30-day

hospital readmissions and inappropriate use of medications. When the services of interest to funders change after a RCT or translation study begins, the study findings about efficacy, effectiveness and cost effectiveness may no longer be important to the funders.

Some programs mandated by the 2010 health reform law are providing or will provide funding for time-limited research and demonstration studies that could result in new information about the efficacy, effectiveness and cost-effectiveness of Alzheimer's and dementia treatments and care practices. Four examples are as follows:

- In 2012, the Center for Medicare & Medicaid Innovation, authorized by Section 3021 of the health reform law, announced 3-year Health Care Innovation Awards to the University of California, Los Angeles (UCLA) and Indiana University for implementation and evaluation of evidence-based coordinated care practices for people with Alzheimer's or other dementias.<sup>135</sup> The UCLA project will provide coordinated care for Medicare and Medicaid beneficiaries with these conditions and is projected to result in \$6.9 million in cost savings. Savvy Caregiver is one component of the project.

The Indiana University project will provide coordinated care for Medicare beneficiaries with dementia or late-life depression and is projected to result in \$15.6 million in cost savings. The project builds on the evidence-based Collaborative Care Model for Alzheimer's Disease and Related Dementias,<sup>66</sup> which was presented at the June 2012 meeting, and subsequent research conducted by many of the same researchers.<sup>136, 137</sup>

- The Medicare Community-Based Care Transitions Program (CCTP), authorized by Section 3026 of the health reform law, is providing funding for community projects to test ways to improve care transitions for high-risk Medicare beneficiaries, including those with cognitive impairment. The Transitional Care Model (TCM) for Cognitively Impaired Elders could be proposed for funding through this program.
- Accountable Care Organizations (ACOs), authorized by Section 3022 of the health reform law, will provide coordinated medical care for Medicare beneficiaries to improve quality and outcomes and reduce costs for unnecessary services. Many of the Alzheimer's and dementia treatments and care practices discussed in this white paper could be delivered in ACOs established through this program.
- Medicaid Health Homes, authorized by Section 2703 of the health reform law, will provide comprehensive medical services for Medicaid beneficiaries with chronic conditions. These health homes are required to offer family support. Many of the evidence-based treatments and care practices for Alzheimer's and dementia family caregivers could be used to meet this requirement.

Positive findings from any of these time-limited projects would not guarantee ongoing financial support. Such findings could, however, help to convince potential funders to pay for the treatments and care practices.

## **Development and use of easily understood concepts and terms to describe and differentiate the treatments and care practices**

Expanding the use of evidence-based Alzheimer's and dementia treatments and care practices into communities across the country will require that community agencies offer them and people with Alzheimer's or other dementias and their family caregivers decide to use them. Ideally, community agencies would offer an array of treatments and care practices to meet the diverse needs of people with these conditions, but agencies certainly cannot offer all of them. To decide which ones to offer, agencies will need to understand what the treatments and practices are, how they differ, where and by whom they are delivered, what they cost, and which people with which kinds of problems are likely to benefit from them. People with Alzheimer's or other dementias, family caregivers and the health care and social service professionals and others who give them advice about care options will need much of the same information.

A classification system, such as described earlier in this white paper, would provide the underlying concepts required to develop this information for potential providers, people with Alzheimer's or other dementias, and family caregivers. The research-based language of a classification system is clearly inappropriate for these people, however. The needed information will have to be presented in language they will understand.

Participants in the June 2012 meeting noted that some of the terms that are currently being used probably create significant barriers to the wider acceptance and use of evidence-based non-pharmacological treatments and care practices. As noted at the beginning of this white paper, the meeting participants recommended against using the term *interventions*. They said this term is appropriate in a research context, but it is unlikely to be understood or meaningful to people with Alzheimer's or other dementias and their family caregivers and may have negative connotations for some of them. They proposed two other terms, *treatments* and *care practices*, which have been used throughout the white paper.

*Non-pharmacological* is another term that is unlikely to be understood or meaningful to people with Alzheimer's or other dementias and many family caregivers. This term defines the treatments and care practices by what they are not, rather than by their intended positive effects. The term may also suggest to some people that medications (pharmacological treatments) and non-pharmacological treatments are mutually exclusive approaches to care. Yet many people with Alzheimer's or other dementias take and benefit from medications that can reduce symptoms for a period of time, and the combined use of medications and non-pharmacological treatments and care practices is often effective. An alternate term, *non-drug*, might be better understood by some people but still defines the treatments and care practices by what they are not and fails to convey their positive effects. As information is prepared for people with Alzheimer's or other dementias and family caregivers, other terms will be needed.

## **Evaluation of alternate ways to connect people to the right treatments and care practices at the right time for them**

Some people with Alzheimer's or other dementias and some family caregivers will be able to obtain treatments and care practices that are right for them by using only the information discussed above. Some may rely on advice from health care and social service professionals or others, who may use the same

information. Aging and Disability Resource Centers (ADRCs) will also be able to use that information. Still, participants in the June 2012 meeting emphasized that other mechanisms will also be needed to connect people to the right treatments and care practices for them.

Most of the evidence-based treatments and care practices discussed in this white paper, and almost all of the multi-component treatments and care practices, begin with an assessment. The heterogeneity of people with Alzheimer's or other dementias and their family caregivers means their care needs vary greatly. An assessment is used to learn about their individual situations and care needs. In some of the existing treatments and care practices, the assessment is highly structured, and its findings lead directly to other components of the treatment or care practice that are intended to address the identified problems and care needs. In other treatments and care practices, assessment is less structured and functions more as a way of helping people with the conditions and family caregivers think about their situations and identify changes that would reduce problems and stress. In the latter treatments and care practices, assessment is ongoing and may be the core or most important component of the treatment or care practice. Between these two extremes, the existing treatments and care practices vary widely in the amount of emphasis they place on assessment and its specific purpose. The meeting participants agreed that assessment is a critical component of any mechanism to connect people to the right treatments and care practices, but they did not recommend particular characteristics of the assessment.

The right treatments and care practices for a person with Alzheimer's or other dementias and his or her family caregiver(s) change over time as the person's condition progresses. Thus, the meeting participants stressed that a mechanism to connect them to appropriate treatments and care practices must be available over the often-long course of the person's condition. People will not need this kind of help continuously but should be able to come back for additional help when their situations and needs change.

Lastly, the meeting participants talked about where the mechanism should be based. One option is to base it in physician offices or medical clinics, as exemplified by the evidence-based Collaborative Care Model for Alzheimer's Disease and Related Dementias.<sup>66</sup> The advantage of this setting is that almost all people with Alzheimer's or other dementias have a physician or other medical care provider, so the mechanism would be available to most people. It would also be available immediately after diagnosis, when it is certainly needed. Another option is to base the mechanism in a community agency, as exemplified by the evidence based T-CARE<sup>®</sup> practice that is being used in Georgia AAAs.<sup>69</sup> Meeting participants who favored this option said that placing the mechanism in medical settings instead could result in overemphasis on medically related treatments and care practices and corresponding under-emphasis on non-medical treatments and care practices. A third option is basing the mechanism in a working partnership between a medical care setting and a community agency, as exemplified by the Partners in Dementia Care (PDC) practice that has been delivered through partnerships between staff of VA medical centers and Alzheimer's Association chapters.<sup>71</sup>

The meeting participants did not reach a conclusion about which option is best. They did agree that evaluating alternate mechanisms for connecting people to the right treatments and care practices at the right time is an important next step in expansion and sustainability of evidence-based treatments and care practices. They also commented that some of the existing mechanisms could be adapted for use in any of the

settings and that different mechanisms and settings could be used in different communities or even in the same community.

### **Ongoing maintenance and regularly updated information about evidence-based treatments and care practices, translation study findings, and sources of financial support**

Participants in the June 2012 meeting noted that researchers, federal and state aging program administrators, health care and social service professionals, and other service providers would benefit from regularly updated information about evidence-based treatments and care practices, translation study findings, and sources of financial support. Ultimately, people with Alzheimer's or other dementias and their family caregivers would also benefit because the availability of updated information would facilitate development, evaluation, expansion, and sustainability of effective treatments and care practices. The meeting participants recommended that a government agency or private organization should be designated to serve these functions.

Such an agency or organization might also convene forums for discussion among researchers, program administrators, health care and social service professionals, and other service providers about difficult issues that complicate the translation process and interfere with expansion and sustainability. Examples of such issues include questions discussed earlier in this white paper, such as whether, and if so when, it is acceptable to incorporate lessons learned from a translation project into an evidence-based treatment or care practice without conducting a new RCT, and what the role of the original researcher(s) should be in translation studies. Other such issues that arise most often when effective treatments and care practices are expanded into the community include who should own a treatment or care practice, who should maintain ongoing training and make decisions about modifications, and whether certification should be required for service providers who deliver the treatments and care practices.

## CONCLUSIONS AND NEXT STEPS

Many non-pharmacological treatments and care practices have been shown in rigorous research to help at least some people with Alzheimer's or other dementias and their family caregivers. These evidence-based treatments and care practices are not well known, and it is sometimes assumed that there are few, if any, such treatments and care practices. That assumption is not correct. Gaps remain, and few of the existing evidence-based treatments and care practices are available at the community level. Still, the number of evidence-based non-pharmacological treatments and care practices is impressive, and additional treatments and care practices are currently being developed and evaluated.

Participants in the June 2012 meeting identified important gaps in evidence-based treatments and care practices for particular subgroups of people with Alzheimer's or other dementias. These subgroups include people in the early and late stages of the conditions, people in racial and ethnic minority groups and those under age 65 who have the conditions; and people with non-Alzheimer's dementias, such as vascular dementia, frontotemporal degeneration (FTD), and Lewy body dementia. The meeting participants recommended research to develop, implement, and evaluate treatments and care practices for these subgroups. They also recommended research on non-pharmacological treatments and care practices to reduce difficult behavioral symptoms associated with Alzheimer's and other dementias. Other important topics for research are treatments and care practices to improve recognition and diagnosis of the conditions, effective ways to coordinate medical and non-medical care, and mechanisms to connect people to the treatments and care practices that are right for them.

Exercise, cognitive training, and treatments that combine exercise and cognitive training are promising practices. The meeting participants emphasized the need for research to determine whether these treatments result in significant positive outcomes, especially for early-stage people.

The current array of evidence-based treatments and care practices is difficult to understand and explain, primarily because there is no generally accepted classification system to categorize the types of treatments and care practices, the characteristics of people who benefit from them, and the kinds of problems they have been shown to reduce or resolve. Participants in the June 2012 meeting identified the development of such a classification system as a high priority next step for making evidence-based treatments and care practices available to people who need them.

The language of a research-based classification system is unlikely to be understood or meaningful to most people who will make decisions about funding, providing, or using evidence-based treatments and care practices. A research-based system would provide concepts, however, that could be adapted with simplified language to create information about the treatments and care practices that is understandable and meaningful to potential funders, providers, people with Alzheimer's or other dementias, and family caregivers. Participants in the June 2012 meeting identified creation of this information as another high priority next step for making the treatments and care practices available to those who need them.

Over the past decade, a surprising number of translation studies have been conducted to test the real-world feasibility and effectiveness of ten of the evidence-based Alzheimer's and dementia treatments and



care practices. Some findings from these translation studies have been published, but many of the studies are still underway or only recently completed. Findings from all these studies provide or will provide valuable information about which treatments and care practices can be delivered effectively by community agencies and result in the same positive outcomes that were found in the original research that established their efficacy. Researchers, program administrators, and community service providers who have led or participated in translation studies should be encouraged to publish their findings.

Additional translation studies are needed to evaluate the feasibility and effectiveness of evidence-based treatments and care practices that have not yet been tested in such studies. Translation studies that involve larger, more diverse samples of people with Alzheimer's or other dementias and family caregivers are also needed.

Findings from translation studies that have tested the same evidence-based treatment or care practice in multiple geographic localities are likely to be particularly helpful in understanding how the characteristics of localities, community agencies, and service providers may affect the delivery and outcomes of a treatment or care practice. The meeting participants recommended that resources should be provided to support analyses of these findings.

A small but growing number of public and private organizations are providing financial support for delivery of some evidence-based treatments and care practices in a few communities across the country. Individuals are also paying out-of-pocket to use a few of the treatments and care practices. This is encouraging and suggests sources of financial support that might be accessed to make other evidence-based treatments and care practices available at the community level. The meeting participants noted, however, that it has taken a long time to obtain the current financial support, and there are substantial restrictions on eligibility for some of the funded treatments and care practices.

The 2010 health reform law (Public Law 111.148) authorized various programs that could support expansion and sustainability of evidence-based treatments and care practices for people with Alzheimer's or other dementias and their family caregivers. At least one of the authorized programs could provide financial support for evidence-based treatments and care practices to help family caregivers. Other authorized programs will support time-limited research and demonstration projects rather than ongoing care and services. Participants in the June 2012 meeting pointed out that findings from such projects could provide new information about treatment efficacy, effectiveness, and/or cost-effectiveness that could increase the likelihood of longer-term financial support from other public and private organizations. They also recommended a comprehensive analysis of the health reform law to identify other programs that could support expansion and sustainability of evidence-based treatments and care practices.

Research and demonstration projects intended to test treatments and care practices for older people in general provide other opportunities to learn about treatments and care practices that might work for people with Alzheimer's or other dementias and their family caregivers. The meeting participants noted that these people should be included as often as possible in such projects, and project findings should be analyzed to determine whether the treatments and care practices worked for them.

Lastly, the meeting participants recommended the identification of a government agency or private organization to provide regularly updated information about evidence-based treatments and care practices, translation study findings, and sources of financial support. Such an agency or organization might also be able to convene forums of interested researchers, administrators, health care and social service professionals, and other service providers to discuss important questions that affect the viability of research in this area, for example, whether, and if so when, it is acceptable to incorporate lessons learned from a translation project into an evidence-based treatment or care practice without conducting a new RCT.

The steps described above will help to consolidate learning from already completed and ongoing research and translation studies. In addition, they will support the development, implementation, and evaluation of new treatments and care practices to fill gaps and the creation of information for potential funders, providers, people with Alzheimer's or other dementias, and family caregivers that will help to move effective treatments and care practices from research to practice at the community level.

## **Appendix A: Meeting Agenda and Attendees**

### **Translating Innovation to Impact: Evidence-Based Interventions to Support People with Alzheimer's disease and Their Caregivers at Home and in the Community**

Grand Hyatt Washington, DC  
1000 H Street, NW

Thursday, June 28, 2012

#### **Objectives**

- Highlight models that have been brought to scale—exploring how they grew from small-to full-scale programs, how they were translated and by whom, how they are tied to payment sources, how many people are served, what translations and implementation challenges they face, as well as successful innovations.
- Discuss models that did not translate well—exploring what implementation issues they faced and the lessons that can be learned from these models
- Identify gaps in the research—looking at what interventions and translations are still needed

#### **Welcome**

8:00 a.m. Registration and Continental Breakfast

9:00 a.m. Introduction, Susan Peschin, MHS, Chief Operating Officer, Alliance for Aging Research

9:15 a.m. Opening remarks: Kathy Greenlee, Administrator, Administration for Community Living, Assistant Secretary for Aging

#### **Session 1: Interventions to Assist Individuals with Dementia**

9:30 a.m. Session Introduction, Shannon Skowronski, Administration on Aging, Administration for Community Living

9:35 a.m. Reducing Disability in Alzheimer's Disease (RDAD), Susan McCurry, PhD, University of Washington Alzheimer's Disease Research Center

9:40 a.m. The Early Identification and Support Project, Michelle Barclay, MA, Minnesota-North Dakota Alzheimer's Association

9:45 a.m. Community-based, Multi-Modal Programs for Persons with Early-Stage Dementia, Sandra Burgener, PhD, APRN-BC, FAAN, University of Illinois, Urbana Campus

9:50 a.m. Panel discussion, Shannon Skowronski, Administration on Aging, Administration for Community Living (Moderator)

10:35 a.m. Open discussion

11:25 a.m. Break

**Session 2: Interventions to Assist the Family Caregiver**

- 11:40 a.m. Session Introduction, Greg Case, Administration on Aging, Administration for Community Living
- 11:45 a.m. Skills2Care, Laura Gitlin, PhD, Johns Hopkins University Center for Innovative Care in Aging
- 11:50 p.m. NYU Caregiver Intervention, Mary Mittelman, DrPH, NYU Comprehensive Center on Brain Aging
- 11:55 p.m. REACH II and Cleveland Managed Care, Leisa Easom, PhD, RN, Georgia Southwestern State University Rosalynn Carter Institute for Caregiving
- 12:00 p.m. Panel discussion, Greg Case, Administration on Aging, Administration for Community Living (Moderator)
- 12:45 p.m. Open discussion
- 1:35 p.m. Lunch

**Session 3: Care Coordination and Care Transitions**

- 2:35 p.m. Session Introduction, Jane Tilly, HHS, Office of the Assistant Secretary for Planning and Evaluation
- 2:40 p.m. Partners in Dementia Care and Care Consultation, David Bass, PhD, Margaret Blenkner Research Institute, Benjamin Rose Institute on Aging
- 2:45 p.m. Transitional Care Model for Cognitively Impaired Elders, Karen Hirschman, PhD, MSW, University of Pennsylvania School of Nursing
- 2:50 p.m. Collaborative Care for Dementia in Primary Care, Christopher Callahan, MD, FACP, Indiana University Center for Aging Research
- 2:55 p.m. Panel discussion, Jane Tilly, HHS, Office of the Assistant Secretary for Planning and Evaluation (Moderator)
- 3:40 p.m. Open discussion

**Closing**

- 4:30 p.m. Closing remarks, Susan Peschin, MHS, Chief Operating Officer, Alliance for Aging Research
- 5:00 p.m. Meeting adjourns

## **Meeting Attendees**

### **Michelle Barclay, MA**

Vice President of Programs  
Alzheimer's Association Minnesota-North Dakota

### **David M. Bass, PhD**

Senior Research Scientist and Vice President for Research  
Margaret Blenkner Research Institute  
Benjamin Rose Institute on Aging

### **Cynthia Bens**

Director, Public Policy  
Alliance for Aging Research

### **Marie A. Bernard, MD**

Deputy Director  
National Institute on Aging, National Institutes of Health

### **Salli Bollin, MSW**

Executive Director  
Alzheimer's Association, Northwest Ohio Chapter

### **Kerry Branick**

Public Health Analyst  
Office of State and Community Programs  
Centers for Medicare and Medicaid

### **Sandra Burgener, PhD, APRN-BC, FAAN**

Associate Professor and Gerontological Nurse Practitioner  
Department of Biobehavioral Health Science  
University of Illinois, Urbana

### **Christopher M. Callahan, MD, FACP**

Director, Indiana University Center for Aging Research  
Indiana University School of Medicine  
Regenstrief Institute, Inc.

### **Greg Case**

Director, Office of Supportive and Caregiver Services  
Administration on Aging  
Administration for Community Living  
U.S. Dept. of Health and Human Services

### **Debra L. Cherry, PhD**

Executive Vice President  
Alzheimer's Association, California Southland Chapter

### **Lindsay Clarke**

Director, Health Programs  
Alliance for Aging Research

**Barney Cohen, PhD**

Director, Committee on Population  
National Academy of Sciences

**Leisa Easom, PhD, RN**

Executive Director  
Rosalynn Carter Institute for Caregiving  
Georgia Southwestern State University

**Gary Epstein-Lubow, MD**

Assistant Professor, Department of Psychiatry and Human Behavior  
Assistant Professor, Department of Health Services, Policy and Practice  
Alpert Medical School of Brown University  
Assistant Unit Chief, Geriatrics  
Butler Hospital

**Lynn Feinberg**

Senior Strategic Policy Advisor  
AARP Public Policy Institute

**Rachel Feldman**

Policy Associate  
National Association of States United for Aging and Disabilities (NASUAD)

**Laura N. Gitlin, PhD**

Professor, Department of Health Systems and Outcomes  
School of Nursing  
Director, Center for Innovative Care in Aging  
Johns Hopkins University

**Elizabeth Gould, MSW, LCSW**

Co-Director, ADSSP National Resource Center  
Alzheimer's Association

**Kathy Greenlee**

Administrator, Administration for Community Living  
Assistant Secretary for Aging  
Administration on Aging

**Lisa P. Gwyther, MSW, LCSW**

Associate Professor, Department of Psychiatry and Behavioral Sciences  
Education Director, Bryan Alzheimer's Disease Research Center

**Karen B. Hirschman, PhD, MSW**

Research Assistant Professor  
University of Pennsylvania School of Nursing

**Mollie Howerton, PhD, MPH**

Health Insurance Specialist  
Centers for Medicare and Medicaid Services

**Beth Kallmyer**

Vice President, Constituent Services  
Alzheimer's Association

**Kathleen Kelly, MPA**

Executive Director  
National Center on Caregiving  
Family Caregiver Alliance

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## Appendix B: Treatment and Care Practice Overviews

The information in this appendix was provided by the nine invited presenters before the June 26, 2012 meeting.

### Reducing Disability in Alzheimer's Disease (RDAD)

*Susan McCurry, PhD*

#### **Background**

RDAD is one of a series of clinically developed and empirically evaluated programs for improving the care of older adults with dementia. It has the unique and synergistic goals of teaching family caregivers behavioral strategies for reducing challenging care-related behaviors as well as increasing physical activity and functioning in their family member with dementia. Caregivers are taught behaviorally-focused strategies for decreasing challenging behaviors characteristic of the disease process, such as depression, anxiety, agitation, and aggression, and taught methods to engage in and encourage physical activity and exercise in order to reduce the physical disability that often results in a loss of independence and a move to more restrictive and costly residential care settings.

RDAD was evaluated via randomized controlled clinical trial and published in one of the most prestigious scientific journals. Statistically and clinically significant differences were obtained: RDAD patients demonstrated 3 month (post-test) and 24-month follow up improvements in physical activity, depression, and mobility/disability. Furthermore, those individuals receiving RDAD were less likely to be institutionalized due to behavioral disturbance throughout the 24 month follow-up period (#RO1 AG10845; Teri et al. 2003. JAMA 290:2015-2022).

To date, RDAD is the only evidence-based approach shown to successfully train community-dwelling caregiver/care recipient dyads to increase the physical activity of individuals with dementia. It is both practical and scalable, having already been tested by interventionists in care-recipient's homes, and providing a systematic and detailed training manual with structured session-by-session outlines, including all participant materials and program assessment tools.

#### **Program Description**

RDAD consists of 12 hourly sessions, conducted in the participants' homes over three months. A structured treatment protocol provides detailed outlines and guidance for each session. Caregivers are taught how to encourage and help individuals with dementia with their exercises (including aerobic/endurance activities, strength training, and methods to improve balance and flexibility) by developing, implementing, and modifying, as needed, individualized behavioral plans.

Caregivers are also taught to identify and modify care-recipient behavioral problems that can impair day-to-day function, adversely affect caregiver/care-recipient interactions, and interfere with exercise participation. They are given specific training regarding how to identify precipitants of care-recipient problem behaviors, how to modulate their own responses to these problems, and how to incorporate

pleasant activities into the exercise program. A comprehensive manual, as well as consultation regarding launching this program, is available.

### ***Current Translational Partnerships***

Since publication, RDAD has been investigated in a variety of settings with an expanding net of potential providers and care-recipients. It is currently being implemented via an AoA grant to the state of Ohio with tremendous success. Preliminary outcome data are promising; providers and care-recipients report considerable satisfaction and eagerness to continue it in their home agencies as well as share their experiences with others, nationwide. Less well-funded but no less enthusiastic activities have been carried out in New Mexico, New York, and are planned for Minnesota. As the evidence for RDAD's success accumulates and community partners adopt and translate it into their community settings, we have benefitted from their feedback for improvements and modifications.

### ***Challenges/Gaps in Knowledge and Future Directions***

As more states come on board and more agencies are engaged, two major rate limiting factors are worthy of discussion:

1. How to support continued program implementation and improvement as the initial grants supporting translational activity end, and who maintains ongoing training and program improvement?

Past funding has enabled us to develop RDAD-support materials that are user friendly to agency staff and evolve with new knowledge from agency providers regarding challenges and barriers to implementation. As new agencies and ideas come to the fore, who funds this additional development? Is it science? Practice? In truth, it is the successful merging of both worlds but unfortunately, this means it 'belongs' to no one and funding remains a question.

2. How to fund service delivery. Sustainability of effective evidence-based programs is essential if we are to truly improve care. Effective translation of any evidence-based program, including RDAD, into the community will require researchers and agencies to work closely together at every stage of implementation to ensure that issues in case ascertainment, treatment delivery, outcome evaluation, as well as the potential for ongoing sustainability are addressed as uniformly and effectively as possible. A myriad of external and internal factors can influence successful translation: agency directors change; staff turnover; reimbursement strategies alter the financial landscape. Agencies have experience with the former; we must all seek to find solutions to the latter.

We cannot sustain programs that are not reimbursable to our agency partners. Currently, RDAD developers have received an NIH grant to investigate RDAD conducted by AAA staff in Washington and Oregon (R01 AG041716). This project has just begun and while we are optimistic about the outcome, we are well aware that in order to maintain program stability and enable growth, these two issues will need to be addressed. Without continued support of the developers and future trainers of these programs and continued methods for revenue to the agencies for providing these services, neither RDAD nor any other evidence-based program will survive in the 'real world'.

## The Early Identification and Support Project

*Michelle Barclay, MA*

### **Background**

The Early Identification and Support Project was designed to increase awareness of Alzheimer's disease (AD) and the need for early diagnosis, improve detection and treatment by physicians, and create or replicate non-pharmacological intervention strategies for people with early dementia and their care partners. A model of support services specifically for people living with MCI (mild cognitive impairment) and early AD was developed. Two programs were piloted, a dyadic support group (Memory Club) and a social engagement program (MeetUp & Mentor). Two workbooks were also published to address the needs of those who could not participate in more formal programming (Taking Action, Living Well).

### **Problems Addressed**

Though more people are being diagnosed with AD early in the disease progression, most receive little information about the disease and how to manage its symptoms. In 2012, an Alzheimer's Association survey of people with early dementia (n=255) identified unmet needs: Information about coping strategies (e.g., how to live with the disease), support (e.g., community resources, learning from others), disease education (e.g., what to expect), and care partner support. 75% reported that they would have found it helpful to speak with another person living with early dementia after receiving a diagnosis and 71% were interested in getting together with others living with the disease.

### **Interventions**

Memory Club is a 10-week dyadic support group for people with MCI / early dementia and their care partners. Dyads meet together for an educational session for the first part of the group (1 hour), then separate into peer groups for the remainder of the session (1 hour). Topics include common issues experienced by people living with early dementia (see Taking Action workbook). First piloted and replicated in Los Angeles, the model was replicated and evaluated at three sites in MN. MeetUp & Mentor is a social engagement program for people with early dementia. The program contains two components: social gatherings (online and in-person), and peer support (trained mentors call newly diagnosed people with early dementia, invite them to meet-up gatherings, and provide social support). A preliminary evaluation was conducted as part of a National Alzheimer's Association social engagement pilot project. The Living Well Workbook is an evidence-based guide to healthy living strategies for people with MCI and early AD.

### **Outcomes**

Memory Club: IADL dependency increased, but care partner perceived effectiveness increased; number of preparation activities increased for care by care partners; high satisfaction with the program by all participants; participants with higher MMSE scores reported increased confidence in carrying out daily tasks. MeetUp & Mentor: very small sample size, trends suggest increases in quality of life, emotional well-being, overall well-being, social satisfaction, and feeling supported. Additional data will be collected on MeetUp only from June–September 2012. Program being replicated in two sites in MN.

### **Challenges / Gaps in Knowledge**

- Recruitment: Few people diagnosed/referred to support early; marketing to general public challenging because everyone self-identifies as “early stage”
- Participation: Attendance is inconsistent, especially in social/“fun” programs (lack of transportation, competing demands)
- Resistance: People with early AD resist participation (lack of insight/denial of diagnosis, fear, stigma)
- Evaluation Challenges: Completing standard evaluation measures challenging for many with early AD; lack of funding for randomized controlled studies, complexities of applied/field research, absence of funding for studying long-term impact of early intervention

### **Resources**

- MeetUp (<http://www.meetup.com/Memory-Mentor/>);
- Taking Action ([http://www.alz.org/mnnd/documents/2010\\_taking\\_action\\_ebook\(1\).pdf](http://www.alz.org/mnnd/documents/2010_taking_action_ebook(1).pdf));
- Living Well ([http://www.alz.org/documents/mndak/alz\\_living\\_well\\_workbook\\_2011v2\\_web.pdf](http://www.alz.org/documents/mndak/alz_living_well_workbook_2011v2_web.pdf))

## **Minds in Motion: A Modal Community Based Program for Persons with MCI or Early-Stage Dementia**

*Sandra Burgener, PhD, APRN-BC, FAAN*

### **Description**

The Minds in Motion (MIM) program is designed to improve or sustain cognitive and physical functioning in persons with early-stage dementia or mild cognitive impairment (MCI). This multi-modal program includes a variety of evidence-based non-drug treatments, translating the science supporting the effects of enriched environments on neuronal functioning. Program components include cognitive training exercises, physical exercises (Tai Chi and Qi Gong), and creative/community involvement activities (writing, art, photography, etc.).

### **Eligibility**

Participants must score >16 on the Mini- Mental State Exam (MMSE) and be willing to participate in therapeutic activities within a social environment. Participants include a variety of dementia types (AD, vascular, Lewy Body, FTD, etc.). Family members (generally spouses) have the option of participating in specific MIM program components, based on their personal needs for support and therapeutic activities, particularly the exercise treatments. Costs are minimal: \$18.00/day or \$180.00 for a 16–20 week semester, with ‘scholarships’ being offered for participants unable to pay the registration fee.

Approximately 30 families are served by the program annually, with average participation rates being 18–20.

### **Methods of Delivery**

Program components are led by a multi-disciplinary team, with the Program Director being a PhD-prepared researcher/clinician. Area experts in various programmatic areas serve as guest instructors for specific topics. Cognitive training materials were developed within a community based program and

tested by Buettner and Fitzsimmons (2008). Additional on-line resources (NIH, AARP, etc.) are used for the cognitive training component. The Tai Chi exercises are led by a trained instructor with 10+ years of experience in leading this exercise form. The program is based in a neutral community setting: a large urban church that is easily accessed. The program is now in its sixth year of continuous offering.

### **Outcomes**

Mental state/executive function (MMSE, Exit 25), depression level (GDS-15), and general functional ability are measured annually. Significantly lower depressive symptoms and improved functioning have been consistent outcomes, with sustained or slightly improved cognitive functioning being evident in ~ 80% of participants annually.

### **Successful Innovations**

Being one of only two such community-based programs in the State of Illinois, the MIM has been able to operate continuously without external funding for over 5 years, representing a sustainable model for delivery of an evidence-based treatment program designed to meet the needs of persons with MCI or early-stage dementia.

As few treatment options are available in the community between the time of diagnosis and need for adult day care, MIM represents a therapeutic treatment in addition to medications, optimizing the opportunities for supporting cognitive and physical functioning. As MIM is a ‘safe’ environment for participants, the stigma associated with dementia is alleviated to some degree.

### **Gaps Identified**

Implementing and directing programs that represent translation into practice require an understanding of both the science and clinical implications of the treatments. These requirements limit the number of qualified professionals to lead these types of initiatives. To fully replicate these models of care, increased professional leadership and funding support for broader participation is required.

## **Skills2Care™ — A Program Provided by Jefferson Elder Care at Thomas Jefferson University**

*Laura Gitlin, PhD*

### **Description**

Skills2Care™ is an occupational therapy based intervention™ for caregivers (21 years and older) and individuals with dementia living at home. It was originally tested as part of the NIH REACH (Resources for Enhancing Alzheimer’s Caregiver Health I: PI, Gitlin). The intervention is designed to reduce caregiver burden, improve caregiver ability to manage daily care challenges, and reduce behavioral symptoms and functional dependence in individuals with dementia. Caregivers are trained in 5 types of strategies to address identified care challenges: communication techniques, environmental modification, task simplification, use of activities to engage individuals with dementia, and taking care of themselves. The Skills2Care™ program can be integrated into occupational therapy services for individuals with dementia in which a comprehensive evaluation is completed (sensory, motor, cognitive functions;

ADL/IADL performance; home environmental hazards) and a plan of care with therapy goals and treatment plan is designed to include Skills2Care™.

### ***Eligibility***

For implementation in community programs—caregivers providing care for an individual with dementia living at home and who report distress associated with such caregiving or need for skills to manage functional decline or behavioral symptoms are eligible. For implementation as an integrated component of occupational therapy service—individuals with dementia for which there is a safety concern, decline in daily function or presence of behavioral symptoms interfering with daily function are eligible.

### ***Delivery Methods***

Skills2Care™ is an in-home program involving assessment of care challenges, didactic instruction, active role-playing, problem-solving tasks, skills training, stress management techniques, and environmental modification. Tailored written materials include an action plan that identifies specific strategies to address the identified care challenge and select resource materials.

### ***Interventionist Training***

To provide the program, training and certification by Jefferson Elder Care, Thomas Jefferson University, is required through a formal training process in which interventionists must demonstrate mastery of skills and adherence to Skills2Care™.

### ***Time Frame***

The program can occur over different time periods depending upon service setting. Typically, the program is delivered over a 2 to 6 month period and can include up to 10 sessions with 3 follow-up supportive telephone calls (depending upon service context).

### ***Trial Outcomes***

Outcomes included statistically significant reduction of caregiver burden, improvement of caregiver skills, efficacy and confidence; reduction in excess functional disability and behavioral symptoms in individuals with dementia and health and improvement in activity engagement and quality of life.

### ***Translations***

Skills2Care™ is being delivered in four settings: Home health agencies through Medicare Part A; Home care practices through Medicare Part B; Area Agencies on Aging through the National Family Caregiver Program; and Jefferson Elder Care—a clinical service at Thomas Jefferson University using Medicare Part B and out-of-pocket reimbursement. The program is being offered in the following regions: Pennsylvania, New Jersey, Massachusetts, Connecticut, Florida, Texas, Washington State, and Ontario, Canada.

### ***Implementation Issues***

Challenges include marketing/recruitment for program enrollment, costs associated with training (\$2,000), scaling up to train occupational therapists nationally versus one agency at a time; restrictions imposed by Medicare reimbursement which limit skills training to caregivers if person with dementia

does not qualify for occupational therapy services; lack of a train-the-trainers program also limits scalability.

### **Successful Innovations**

Skills2Care™ benefits both the person with dementia and their caregiver. It can be embedded in various clinical settings and its visit structure is flexible so that it can easily be translated to meet location/reimbursement requirements.

## **NYU Caregiver Intervention**

*Mary Mittelman, DrPH*

### **Background**

A randomized controlled trial of NYU Caregiver Intervention with 406 spouse caregivers randomly assigned to intervention or usual care control group, followed for up to 18 years, demonstrated the intervention's significant short and long-term effects on caregiver well-being and ability to avoid or postpone nursing home placement of persons with dementia. Intervention effects were replicated in 3 Country Study in US, UK and Australia. Effects were achieved by improving social support of family and friends.

Six demonstration projects are underway with AoA ADSSP support; VA demonstration project at 2 VA centers; randomized controlled trial in Hispanic population of upper Manhattan compared to case management, and in Israel, compared to control group participation; 3 pilot studies were funded by Rosalynn Carter Institute.

More than 1,000 older adults and caregivers participated in these projects (including controls).

### **Problems Addressed by the Intervention**

- Isolation of spouse caregiver;
- Caregivers' need for support from family members;
- Lack of understanding of effects of symptoms of dementia on the person with the illness, spouse and family;
- Lack of awareness of available resources in the community;
- Lack of accessible expert to help caregiver deal with problems as they arise.

### **Assistance Provided**

- Help caregiver and family members come together to help each other and the person with dementia;
- Educate the caregiver and family members about the effects of dementia and how best to care for the ill relative, for themselves and for each other;
- Provide information, guidance and referral to community resources;
- Be an expert sympathetic listener.



### ***Main Intervention Components***

- Comprehensive assessment of caregiver needs and available support;
- Individual counseling (2 sessions) and family counseling (4 sessions) within 4 months of enrollment;
- Ongoing counseling and support from original interventionist;
- Regular support group participation.

### ***Proven Outcomes***

- Improved long term (> 5 years) satisfaction with support from family and friends;
- Significant long-term (> 3 years) effects on caregiver symptoms of depression;
- Reduced reaction to problem behaviors of the person with dementia (> 4 years);
- Improved caregiver self-reported physical health and number of physical illnesses (> 1 year);
- Major extension of time to nursing home placement of the person with dementia (average >1.5 years);
- Effects on depression and burden last through nursing home placement and death of person with dementia.

### ***Delivery Characteristics***

- Individual and family counseling delivered in person; additional counseling available by telephone and email;
- Long-term relationship with participants;
- Interventionists: Bachelor's or Master's level social workers, nurses, or other related disciplines with clinical experience working with families, understand the effects of dementia and the cultural context of care.

### ***Key Features***

- Individualized to needs of each caregiver and family, based on written assessment and interview;
- Includes family members of primary caregiver;
- Education and training about stages of dementia and effects on person with the illness, caregiver and family;
- Ongoing support for duration of illness, whether person with dementia is at home or in residential care;
- Six individual and family sessions and availability of interventionist have long term effects on caregiver support;
- Benefits far exceed cost, as the average participant can keep person with dementia out of a nursing home for about a year and a half, while maintaining or improving caregiver support and mental and physical health.

### ***Challenges/Gaps in Knowledge***

- Promoting benefits of participating in NYUCI to caregiver, family and health and social care providers;
- Helping caregivers understand the value of involving family members;
- Providing in-person training in a timely manner for interventionists;

- No third party reimbursement creates problem for sustainability.

### **Innovations**

- Online training, with certification and licensing is currently under development and will be available by mid-2013;
- The intervention has shown promise for producing significant benefits when primary caregiver is an adult child;
- We are planning a major new initiative in which the intervention can be delivered entirely through web-based mechanisms to family members who are at a distance from each other and from a trained provider.

## **REACH II and Cleveland Managed Care Georgia Care Consultation (Translation of Cleveland Managed Care)**

*Leisa Easom, PhD, RN*

### **Description**

Georgia Care Consultation is an evidence-based telephonic program designed to serve persons with Alzheimer's disease or related dementias and their caregivers. The intervention empowers clients to manage care and make decisions more effectively. The program is both standardized and tailored with a focus on preventing crises by helping clients prepare for changes and plan for the future.

### **Eligibility**

The 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 eligible.

### **Methods of Delivery**

Trained Care Consultants with a college degree in social work, nursing, or other related field, follow a telephone contact protocol to perform an ongoing triage assessment to identify caregiving issues. The Care Consultant and client then develop Action Steps to achieve a goal with periodic progress evaluation. All assessments, protocol contacts, and Action Steps are prompted and recorded in the Care Consultation Information System (CCIS) computer program.

### **Time Frame**

The Care Consultant initiates phone contacts at regular intervals for 12 months. First contact is at the time of enrollment; contacts are then made every two weeks for the first two months; once per month during months 3 through 6; then every three months during months 7 through 12, for a minimum of 10 contacts. Additionally, the clients are encouraged to contact the Care Consultant on an as needed basis.

## **Outcomes**

Preliminary data reveals a decrease in caregiver depression, stress, and burden. Caregivers and care receivers report reduced relationship strain, embarrassment and isolation as well as improved access to community resources.

## **Selected Translations of Cleveland Managed Care Following Original Studies**

- Partners in Dementia Care for Veterans and Their Family Caregivers, 2006–2011 (508 veterans with diagnosed dementia and 486 caregivers)
- Integrated Care Management, 2005–2007 (79 older adults with multiple chronic conditions and 24 caregivers)
- Care Network for Depression for Older Adults and Family Caregivers, 2006–2009 (76 older adults with diagnosed depression and 21 caregivers)
- Care Consultation in Cleveland, Ohio, 2009–2011 (54 older adults with chronic health conditions and 39 caregivers)
- Care Consultation in Tennessee, 2009–2012 (continuing to enroll: currently 36 older adults with diagnosed dementia and 33 caregivers)
- Care Consultation in Georgia Area Agencies on Aging, 2010–2013 (continuing to enroll: currently 489 older adults with diagnosed dementia and 477 caregivers)
- Replication of Partners in Dementia Care for Veterans and their Caregivers in Ohio, 2011–2013 (enrollment begins July 2012).

## **Translational and Implementation Issues**

- Care Consultant training on Alzheimer’s disease and problem solving; embedding a distinct program (marketing/recruitment) within an established intake center
- Blending the CCIS with established referral and client databases; attrition of enrollees.

## **Successful Innovations**

- Implementation of Care Consultation within Area Agency on Aging
- Refinement of the computer application used to deliver Care Consultation
- Systematic outreach and marketing.

## **Gaps Identified**

1. The impact on attrition of adding one face to face contact;
2. Cost effectiveness is needed, i.e. pre and post intervention.

## **GA REACH (Translation REACH II/REACH VA)**

*Leisa Easom, PhD, RN*

### **Description**

GA REACH (Resources for Enhancing Alzheimer’s Caregiver’s Health) is a multicomponent intervention for caregivers (21 years and older) of individuals with Alzheimer’s disease or dementia. The intervention is designed to reduce caregiver burden and depression, improve caregivers’ ability to

provide self-care, provide social support, and help caregivers learn to manage difficult behaviors in care recipients. The intervention allows for tailoring to meet the specific needs of the caregiver.

### **Eligibility**

Caregivers providing care for an individual with Alzheimer's disease for at least 4 hours/day with reported distress associated with such caregiving.

### **Methods of Delivery**

Didactic Instruction, role-playing, problem-solving tasks, skills training, stress management techniques, and telephone support groups. A resource notebook (Caregiver Notebook) contains written educational materials. Certification of interventionist occurs via a formal training process which requires demonstration of mastery of skills.

### **Time Frame**

The program occurs over a period of six (6) months and includes the efforts of both an Interventionist and a Group Leader. The interventionist provides nine home (individual) sessions lasting one hour each, and three telephone (individual) sessions lasting up to ½ hour each. The Group leader guides and facilitates five structured telephone support group sessions (5-6 group members) reviewing topical information and sharing experiences and concerns that last up to 1 hour each.

### **Outcomes**

Statistically significant reduction of burden, depression; improvement of caregiver health.

### **Selected Translations**

REACH VA (translated by Memphis VA Medical Center into 24 VA Medical Centers, n = 127 dyads)

Scott & White Family Caregiver Program (translated by Scott & White Healthcare into Scott & White Memorial Hospital, n = 158 dyads)

REACH OUT (translated by Southern Caregiver Resource Center into local Hispanic community, n = 29 dyads)

GA REACH (translated by RCI into a rural community, n = 85 dyads);

GA REACH(translated by RCI into Coastal GA Area Agency on Aging, n = 14 dyads, continuing to enroll)

The Alzheimer's Disease Supportive Services Program within the Administration on Aging has funded translations in a number of states: North Carolina Department of Health and Human Services, Nevada Department of Health and Human Services, Florida Department of Elder Affairs, North Carolina Department of Health and Human Services, Arizona Department of Economic Security, Tennessee Commission on Aging and Disability, and Alabama Department of Senior Services.

### **Translational and Implementation Issues**

Challenges to implementation include marketing/recruitment for program enrollment, agency staff “buy-in,” time management of interventionists, and attrition of enrollees.

### **Successful Innovations**

English to Spanish translation of REACH materials with Hispanic population (Cuidar program), creation of additional module for interventionists on safety precautions for home intervention, flexibility of point of site delivery; caregiver prompts embedded into hospital EMR, adoption by Healthcare System in TX led to identified funding stream and expansion into 2 additional hospitals and multiple primary care clinic.

REACH VA is now available across the VHA system due to funding authorized and approved by Congress through the Department of Veterans Affairs.

### **Gaps Identified**

1. Modification of intervention dosage;
2. Cost effectiveness is lacking, i.e. pre and post intervention.

## **Partners in Dementia Care and Care Consultation**

*David Bass, PhD*

### **Background**

- Two original research/demonstration projects focused on dementia population;
- Seven replications completed or underway: 4 dementia, 1 depression, 1 multiple conditions, 1 no disease restriction;
- More than 5,000 older adults and caregivers participated in these projects (including controls).

### **Problems Addressed:**

- Fragmentation between health and community services;
- Lack of attention to caregivers by health care providers;
- Lack of coordination between formal and informal care;
- Difficulties understanding diagnosis/treatment and dealing with changes in illness and care;
- Lack of follow-through and planning by persons with illness and caregivers.

### **Assistance Provided**

- Care coordination between health and community services, and among community services;
- Personalized coaching and information;
- Linkage to and monitoring of services;
- Strengthening the network of family and friend helpers;
- Emotional support throughout caregiving journey.

### ***Delivery Characteristics***

- Delivered by telephone and email (appropriate for long-distance and rural caregiving);
- Long-term relationship with clients
- Efficient and low cost—a full-time Care Consultant, with part-time administrative support, serves 125 families;
- Bachelor's or Master's level social workers, nurses, or from other disciplines;
- More focus on solutions and action plan—less focus on assessment;
- Protocol assures at least minimum number of contacts even when no acute problems.

### ***Key Features***

- Empowers consumers—consumers do the work, which is guided by their preferences and priorities;
- Targets both person with illness and caregiver—for all levels of disease severity;
- Focuses on simple and practical solutions for immediate concerns and prevention;
- Uses standardized protocol but personalized content;
- Improves communication with health care providers;

### ***Care Consultation Information System (CCIS) and Outcomes Model***

Main Intervention Components:

1. Broad Trigger-focused Assessment;
2. Action Plan comprised of achievable tasks to address consumer-identified problems,
3. Ongoing Monitoring and Reassessment.

### ***Proven Outcomes***

- Decreased hospital, emergency department, and nursing home use by persons with illness;
- Increased primary care, community service, and support service use by persons with illness and caregivers;
- Increased quality of formal and informal care;
- Decreased depression and care-related strain for persons with illness and caregivers.

### ***Challenges/Gaps in Knowledge***

- No third party reimbursement—health plans considered paying but need more data on healthcare cost savings;
- Getting a sufficient volume of clients when marketed directly to consumers—more successful marketing when consumers are steered to program by physicians, health plans, or others involved with clients;
- Obtaining more information on whether and how much consumers are willing to pay for Care Consultation;
- Clarifying when to discharge since Care Consultation is an ongoing service;
- Interfacing the CCIS with organization's existing information technology;
- Distinguishing Care Consultation from case management and information and referral;
- Identifying niche for Care Consultation within organization's and community's existing services;

- Achieving long-term engagement of clients who are not in crisis—focus on prevention is time limited;
- Getting experienced case managers to follow a less intense, lower-cost service model.

## **Transitional Care Model for Cognitively Impaired Elders**

*Karen Hirschman, PhD, MSW*

### **Brief Overview**

Given the expected growth of older adults coping with complex chronic conditions, including Alzheimer’s disease and other dementias, rapidly rising healthcare costs and a projected shortfall in the Medicare Trust Fund, there is an urgent need to promote older adults’ access to high quality, cost-effective and efficient services such as those provided via the TCM.

The TCM has been tested and refined for more than 20 years by a multidisciplinary team of clinical scholars and health service researchers from the University of Pennsylvania, in three clinical trials with cognitively intact older adults and one trial with cognitively impaired older adults and their family caregivers.

The TCM targets older adults with two or more risk factors, including a history of recent hospitalizations, multiple chronic conditions and poor self-health ratings. Major components of this model are:

1. the use of master’s prepared transitional care nurses (TCNs) with advanced knowledge and skills in the care of this population, as the primary coordinator of care to assure continuity throughout acute episodes of care;
2. in-hospital assessment, collaboration with team members to reduce adverse events and prevent functional decline, and preparation and development of a streamlined, evidenced-based plan of care;
3. regular home visits by the nurse with available, ongoing telephone support (seven days per week) through an average of two months post-discharge;
4. continuity of medical care between hospital and primary care providers facilitated by the TCM accompanying patients to first follow-up visits;
5. active engagement of patients and family caregivers with a focus on meeting their goals and working collaboratively with multiple health care providers across episodes of acute care.

The TCM has consistently demonstrated improved quality and cost outcomes for high-risk, cognitively intact and impaired older adults when compared to standard care in: reductions in preventable hospital readmissions for both primary and coexisting health conditions; improvements in health outcomes; enhanced patient satisfaction; and a reduction in total health care costs.

### **Translating Research into Practice**

Despite the evidence establishing the linkage between TCM and enhanced value, a number of organizational, regulatory, financial and cultural barriers have prevented the model’s adoption. In

response to these challenges and with the support of a number of foundations, the Penn team formed partnerships with leaders of the Aetna Corporation (Aetna) and Kaiser Permanente Health Plan (KP) to translate and integrate the promote widespread adoption of the model by demonstrating its effectiveness among at-risk, chronically ill older adults.

Guided by a national advisory committee, this effort included the design and pre-testing of a number of tools including a screen to identify high-risk older adults, a set of web-based training modules to prepare nurses to implement the evidence-based intervention, an information system that houses the clinical assessment instrument, intervention protocol and documentation system, and consistent quality improvement and monitoring procedures. New workflow processes were designed to integrate the

TCM, as an extension of Aetna’s high-risk geriatric telephonic case management program. The findings of this translational research effort have resulted in TCM being identified as a “high value” proposition by Aetna leaders. Based on the improvements in health outcomes, member and physician satisfaction and the reductions in re-hospitalizations and total health care costs observed in the Aetna project, the University of Pennsylvania Health System (UPHS) has adopted TCM as a service and local insurers are reimbursing UPHS for delivery of TCM to their members.

The TCM has been recognized as an effective approach to care that, if scaled, could accelerate efforts to move from a fragmented to an integrated, high performing health care system. For example, in 2010, the TCM was recognized by the National Quality Forum as a preferred practice [No. 21] as part of the consensus report focused on care coordination, specifically addressing the high-risk needs of patients and family caregivers in need of, and throughout challenging transitions in health and health care.

Additionally in 2011, the TCM was one of a few program models identified by the nonprofit, nonpartisan Coalition for Evidence-Based Policy as meeting the congressionally-based standards for Top-Tier Evidence. Supported by the MacArthur Foundation and Edna McConnell Clark Foundation, the Coalition’s independent findings are shared with members of Congress and other legislative groups to promote uptake of proven solutions.

## **Collaborative Care Model for Alzheimer’s Disease and Related Dementias**

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### **Background**

- Most older adults with dementia receive a majority of their care in primary care settings
- Primary care is not adequately prepared for the care of older adults with dementia
- Current treatments for dementia and related symptoms remain controversial
- Model is based in primary care but team is designed to coordinate medical care and community services while also providing direct care and accessing specialty care
- Model includes team-based care, standardized protocols, information technology, and an advanced practice nurse to assure right patient, right treatment, at right time



- Model focuses on education, training, and support of family caregiver but also stresses non-pharmacologic approaches to medical treatment and partnership with primary care
- Collaborative care for dementia improved quality of care, satisfaction, patient behavioral symptoms, caregiver stress, and appropriate use of medications

### ***Main Limitations***

- Model requires system redesign, relatively expensive providers, and a change in the cultural and organizational behavior of the targeted care sites
- Medicare does not reimburse providers for the costs of collaborative care
- Studies have not been completed to demonstrate differences in rates of nursing facility use, but payers often seek this evidence to pay for upfront costs of system redesign
- A primary care provider typically provides care to only ~25 older adults with dementia

### ***Dissemination Efforts***

- Realign the interests of patients and families with interests of providers and Medicare
- Expand the scope of collaborative care for dementia to incorporate other chronic conditions such as mild cognitive impairment, depression, and cardiovascular disease
- Move much of the direct patient contact by the RN or social workers into the home and out of primary care but keep the program based in primary care
- Adapt information technology to support population-based care
- Implement redesigned collaborative care model at urban public hospital
- Develop implementation guidelines, written protocols, and freestanding EMR

### ***Lessons Learned***

- Any implementation effort requires adaptation of the model to local realities
- Organizational change and system redesign are much larger barriers than training providers in new care model or supplying new resources
- People who develop new models have expertise that does not necessarily reflect the expertise needed to implement new models or take them to scale nationally
- Incentives and disincentives for model implementation can change rapidly and often

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