Implementing a Community-Based Program for Dementia Caregivers

an Action Guide using REACH OUT

"This brief yet incredibly rich Action Guide offers a can-do, evidence-based public health approach for the real world of service providers supporting Alzheimer's family caregivers. Sidebar boxed tips provide pearls from seasoned, grounded clinician-scientists. The Guide is careful not to overwhelm or over-promise program directors and providers. Rather, the writing style and sequenced process based on the RE-AIM public health framework sets realistic expectations while appropriately warning of landmines along the way. I'm betting An Action Guide Using REACH OUT will encourage aging and mental health services to expand their menu of evidence-based chronic disease services for Alzheimer's family caregivers. "

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Acknowledgements

Introduction

REACH OUT is one of several evidence-based caregiver support systems designed to promote the health and well-being of adults caring for persons with dementia. *Implementing a Community-Based Program for Dementia Caregivers: An Action Guide using REACH OUT* provides a step-by-step approach to using REACH OUT in communities of varying size and composition. Much of what appears in this Action Guide can be applied to other evidence-based programs and is intended to facilitate expansion of caregiver interventions and promote their adoption into widespread practice.

Who are family caregivers?

Our nation increasingly relies on family members or friends for needed care and support as we age. At present, family caregiving impacts one of every five American households.[1] More than 34 million of us provide informal, unpaid care to an adult suffering from an illness or disability, enabling our loved ones to remain in their own homes and communities as long as possible.

Because of our longer lifespans, a continued commitment to community-based care, and the tremendous value of informal home care (an estimated $350 billion savings in 2006),[2] family caregiving is expected to become even more commonplace.[3]

Family caregivers typically assume their caregiving role willingly and reap personal fulfillment from helping a family member, developing new skills, and strengthening family relationships.[4] For these benefits, however, caregivers often sacrifice their own health and well-being. Depression, anxiety, use of psychoactive medications, poor physical health, and compromised immune function are more common among family caregivers than adults not providing such care.[5,6,7,8] In addition, the declining health of caregivers can compromise their ability to provide care to others.[9]

The challenges and demands of caregiving are further compounded when the care recipient is cognitively impaired. Among caregivers of people aged 60 years or older, nearly one in three (about 29.1%) supports someone with a cognitive impairment, a memory problem, or a disorder such as Alzheimer's disease.[10]   Because these caregivers are relied upon to manage behavioral disturbances, attend to physical needs, and provide seemingly constant vigilance,[11][12][13] they report higher levels of burden, stress, and depression than caregivers dealing with physical problems alone.[10]

How did REACH OUT evolve?

Recognizing the unique needs of family caregivers for people with dementia, the research community has been pursuing multiple avenues to identify effective interventions that support caregivers and improve their health and well-being. One of these evidence-based interventions, recently highlighted by the Institute of Medicine for implementation by public, private and community organizations, is Resources for Enhancing Alzheimer's Caregiver Health, commonly referred to as REACH.

The REACH intervention is the result of two clinical trials sponsored by the National Institutes of Health (NIH). In the first trial (REACH I), initiated in 1995 by the National Institute on Aging (NIA) and National Institute for Nursing Research (NINR), each of six sites tested different strategies to help dementia caregivers manage the stress and burden of their caregiving roles. A quantitative analysis of results of the sites' collective five-year experience yielded a new intervention design subsequently tested across five sites in a randomized clinical trial (REACH II) funded by the same institutes in 2001. REACH II recognized the complexity of the problems causing caregiver stress and burden, and their tendency to vary in severity from one caregiver to another. To address these problems, research interventionists worked with caregivers to provide multiple components: education on dementia and caregiving; "active" skills training on techniques for pleasant events or relaxation; guidance in making the physical environment safer; and instruction and support for improving physical self-care, accessing social support, and writing "behavioral prescriptions" for managing various limitations of Activities of Daily

Living (ADL), Instrumental Activities of Daily Living (IADL), and behavior problems. An initial risk appraisal shaped the order of intervention components and the intensity of their application.

The REACH II intervention was delivered over six months through nine in-home visits, interspersed with three therapeutic telephone sessions and five support group sessions conducted with a specialized phone system. Findings showed significantly greater improvements in quality of life and depression in the intervention group, specifically:

- Decreased behavior problems by 36.3%
- Increased social support by 24.1%
- Improved caregiver self-care by 13.6%
- Decreased depression by 39.0%
- Decreased caregiver burden by 23.1%.

Building on the success of these clinical trials, the next hurdle was to translate the REACH II intervention for feasible use in community-based settings. In 2004, the Administration on Aging accepted this challenge by awarding a grant to the Alabama Department of Senior Services to implement this intervention with four Area Agencies on Aging (AAA). Researchers from The University of Alabama partnered on the project, providing training and evaluation expertise as well as overall project guidance and management. Consistent with procedures used in Community-based Participatory Research (www.ahrq.gov/downloads/pub/evidence/pdf/cbpr/cbpr.pdf), an Advisory Committee of key stakeholders participated in all design and delivery decisions to ensure full consideration of the realities of the healthcare and social environments. The eventual intervention product, termed REACH OUT (Resources for Enhancing Alzheimer's Caregiver Health: Offering Useful Treatments), was delivered to 272 dementia caregivers. Its protocol reduced the number of treatment components (from seven to five), required fewer home visits, and shortened the time span (from six months to three to four months).

As with the earlier trials, the REACH OUT intervention resulted in significant positive changes in caregivers' stress and burden. These included:

- Improvement in overall health and depression
- Reductions in feelings of burden from caregiving
- Fewer feelings of anger towards the care recipient.

Benefits accrued to care recipients as well; they were less likely to be left unsupervised, wander, and have access to dangerous objects. Overall, both caregivers and case managers were very satisfied with the type and quality of services provided and with all treatment components.

These successful outcomes of the REACH OUT intervention demonstrated that the REACH II intervention can be modified for feasible and effective use in AAAs. Through funding from the Rosalynn Carter Institute for Caregiving (www.rci.gsw.edu), several refinements to further improve program quality and impact have been incorporated into the design.

Why an Action Guide?

Evidence-based interventions are only as good as their implementation. With current knowledge about REACH OUT and other evidence-based caregiver support interventions, it is incumbent on us to broaden their application and integrate them into ongoing service delivery. Thus, this Action Guide is designed for use by agencies at state and local levels that currently offer, or are considering adding, services for older adults with dementia. Included in this audience are aging services or grass roots organizations such as State Units on Aging, senior centers, faith-based organizations, hospital outreach programs, home health agencies, and other public and private community-based entities.

The Action Guide offers a step-by-step process for implementing REACH OUT in communities of varying size and composition, while maintaining the integrity of its evidence-based design. It provides relevant examples, tips, resources, websites and additional references to bolster understanding of the intervention and its translation in a community setting. The underlying foundation for the Guide is the RE-AIM framework, which helps guide implementation of dissemination-ready interventions or programs.   Through a series of specific questions and analyses, RE-AIM bridges the gap between research and practice and helps program planners, evaluators, and policymakers maximize the chances for successful implementation of feasible interventions in real-world settings.

Section I: *Designing the Blueprint* helps confirm that your agency is indeed ready to implement a dementia caregiver intervention program. Although REACH OUT is a translated program, you may find it necessary to tailor the intervention to your unique situation as you select program settings, garner organizational support and resources, form an Advisory Committee, and solidify the intervention design and protocol.

Section II: *Laying the Foundation* offers advice for planning the intervention assessment, modifying two fundamental program resources (the Case Manager Training Manual and Caregiver Notebook), and training case managers.

Section III: *Making It Happen* guides you through caregiver enrollment, the early stages of implementation, and ongoing support for case managers as they deliver the intervention.

Section IV: *Taking Stock* focuses on tracking implementation and assuring program sustainability.

While the steps in each section are presented sequentially, in practice several of them may occur concurrently. We encourage you to read through the entire guide to familiarize yourself with the process and challenges that lie ahead—and to know the wealth of resources that are available to inform and support your efforts. Then proceed thoughtfully through each section to boldly and creatively bring this evidence-based intervention to our nation's expanding group of caregivers.

Please note that you can implement REACH OUT through the information and resources provided in the Action Guide and the Appendix, assuming that there is a staff development office in your facility. However, we strongly recommend obtaining official case manager or train-the-trainer certification through the University of Michigan Department of Medical Education (UMDME). Individuals earn certification following an intensive day-and-a-half workshop, and receive Trainer and Caregiver Notebooks as well as additional materials to facilitate accurate implementation of REACH OUT. The University of Michigan requests that those choosing to implement the program in the absence of certification register on the website so that the University can track the use of REACH OUT. For more information on certification and training, visit www.iog.umich.edu/reachout/reachout.htm.

Step 1: Confirm the "readiness" for a caregiver intervention program

The first, and perhaps most important, step in implementing REACH OUT in your community is to determine whether you are "ready" for such a program. Four key questions, derived from similar methods used in community-based participatory research, can help shape your deliberations and ultimate decision.

1. Is your agency or network of agencies willing to utilize evidence-based health programs and stay true to the REACH OUT program?
2. Is there strong buy-in from senior leadership and key partners as reflected in both programmatic and financial support?
3. Is there funding for the program, either new funding and/or willingness to reallocate current resources to support evidence-based health programming?
4. Is there access to personnel with the expertise to implement the program and to the population that needs the program?

Among the many tools for assessing readiness are several that relate specifically to aging populations:

- North Carolina Aging and Disability Resource Connections (ADRC) Community Readiness Assessment Tool, designed to facilitate an objective discussion between organizations, agencies, and institutions about how information, referral, and assistance is delivered to consumers in the community who need long-term services and supports.
  Available at www.dhhs.state.nc.us/olts/what/ardc_complete_assessment.pdf

- Evidence-Based Healthy Aging Programming: Tools & Checklists, from the National Council on Aging (NCOA), Center for Healthy Aging, provides a framework for discussions within a community aging service provider organization or among partnering organizations interested in offering evidence-based health promotion and self-management programming. Available at www.healthyagingprograms.com/resources/CHA_Tools_Checklists.pdf

- The Aging and Disability Resource Center, Technical Assistance Exchange, also has valuable information on readiness.
  Available at www.adrc-tae.org/tiki-index.php?page=Readiness

Step 2: Select program settings

Once you are confident with your "readiness," you can begin shaping your program.

Do you want to implement REACH OUT in one single agency (e.g., a senior center, a faith-based organization, a home health agency, or a hospital outreach program) or are you in a position to support a more expansive implementation (i.e., one that covers a metropolitan area, a larger district or region, or the entire state)? If the latter, you will want to consider an entire network of agencies: Area Agencies on Aging (AAA) through-out the state, home health agencies in a region, senior centers throughout a city, or a combination of agen-cies. You might also want to strive for a mix of rural and urban settings, taking into account the benefits, feasibility, and trade-offs of driving longer distances for home visits.

❗ Tips for Case Managers: Balancing Urban and Rural Areas

People living in rural areas have a great need for outreach, given the long distances they must travel to obtain services and their limited transportation options. Yet, the more time case managers spend on the road, the less time they will have for client interaction. This may mean fewer home visits or lower caseloads. Substituting telephone intervention for some of the face-to-face interaction is undeniably tempting when delivering REACH OUT in rural areas; however, the intervention has been shown to be less effective with this modification. In addition, while creative use of technology (e.g., interactive videophones) may help overcome some of the challenges inherent in rural settings, there is no empirical evidence that shows that these innovative methods are effective.

The RE-AIM framework, described briefly in the Introduction, can be helpful in gathering appropriate information to examine optional program settings and guide decision making.

- For more information on RE-AIM, see www.re-aim.org. This website includes information for community and healthcare providers who plan to implement health behavior interventions.

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Step 3: Assure organizational support and resources

You will need to secure some basic resources to get your program off the ground and manage it successfully over time. Specific requirements will vary depending on your agency's unique situation and circumstance and the scope and intensity of your program design. Use the following list as a guide and tailor it as you see fit.

Organizational Support
Meet with the leadership of your agency or network to gain explicit support of the administration. With true buy-in from the director, you will have a ready and effective program champion. You will also want to involve as early as possible any staff likely to be case managers or to supervise case managers. Strive to integrate the new program into routine, ongoing agency services so that it becomes one of a menu of caregiver offerings.

Human Resources
You will need a team of personnel to plan and implement your program. Using the guidance provided below and your agency's standard hiring procedures, identify a pool of candidates for all program positions, interview those most qualified, make your selections, and arrange to bring them on board or reassign them as expeditiously as possible.

- **Program coordinator**: Responsible for overall coordination and management of program planning, implementation, and evaluation.

- **Case managers**: Responsible for conducting and evaluating the effects of the program.

   The maximum caseload is approximately 10–12 clients per case manager. The actual caseload depends upon how widely the program is to be implemented, the mix of urban and rural settings you choose, and whether case managers are dedicated to the REACH OUT intervention. One strategy is to start small and gradually expand. This way, the kinks can be worked out in implementation prior to broader expansion.

We recommend that case managers have at least a bachelor's degree and be certified by succesfully completing a training workshop through the University of Michigan Department of Medical Education (UMDME) or provided through your agency by a UMDME-certified trainer (see Steps 8 and 9). In addition, some clinical experience in social work, nursing, or other health or human service delivery field is preferred because case managers will be called upon to make some clinical judgments and to link assessments with intervention plans. However, staff with bachelor degrees in any of the social sciences, but no additional relevant experience, can also be considered – particularly if their program offers ongoing support from supervisors or other experienced personnel through weekly case reviews, phone consultations, hotlines, etc.

There may be staff currently on board who would make excellent REACH OUT case managers. If so, consider reassigning them to the REACH OUT program, either full- or part-time. If the role is spread across several staff, be sure they are trained equivalently and, if possible, have the same supervisor. Even if you anticipate needing only one case manager, we strongly recommend that you select and train a second staff member as "backup" in case of sickness, extended leave, vacation, or turnover. This individual could be the case manager's supervisor.

- **Supervisors**: Responsible for clinical oversight and support.

Supervisors, ideally certified by UMDME, should have a deep understanding of the REACH OUT program and be available to case managers for regular discussions and consultations. These interactions can include weekly case conference reviews, supplemented by reserved "office hours" once or twice a week when case managers can call from the field to ask questions. Consultation will be most common when the newly trained case manager first begins making home visits, as well as when an unusual or unexpected behavioral disturbance occurs requiring extensive tailoring of the intervention (see Step 12 for further discussion of the supervisors' role).

"The collection of data to document impact and effectiveness is vital for program survival and growth. "

- Case Manager

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- **Evaluators**: Responsible for data collection.

  Ongoing evaluation of your program is critical. Oftentimes this activity is overlooked and undervalued, but the collection of data to document impact and effectiveness is vital for program survival and growth. It can be accomplished simply and cost-effectively by asking your case managers to collect data while visiting families in the field. However, if funds are available, the preferred option is to employ personnel not involved in the intervention in order to avoid the possibility of bias.

- **Data analysts**: Responsible for data entry and analysis.

  Since analysis consists primarily of pre- and post-intervention comparisons, some agencies may be able to rely on in-house program evaluation capability. Others may choose to partner with a nearby university to make this task more manageable.

- **Trainer**: Responsible for designing, conducting, and evaluating case manager certification.

  All case managers must be trained and certified in REACH OUT before contacting caregivers and making their first home visit. It is highly recommended that case managers receive training and certification from the UMDME. However, if you have a qualified trainer on staff or have access to trainers from a nearby university, you may be able to conduct training on your own by using this Action Guide and the Appendix (see Steps 8 and 9 for detailed information on carrying out this role). If you choose the latter strategy, establishing a UMDME consulting agreement will facilitate implementation.

Other Resources
A small budget should be anticipated to cover program materials such as:

- CD players, CDs, and headphones for caregivers to listen to music
- Printing of training materials, forms, logs, etc.
- Books for family members of all ages about dementia
- Calendars to post on caregivers' refrigerators or walls to help them keep track of your home visits and phone calls, medical appointments, etc.

For more information on training and certification, see www.iog.umich.edu/reachout/reachout.htm.

Using Volunteers for REACH OUT

To date, all individuals involved in REACH OUT have been paid staff, not volunteers. If you are considering using volunteers, the following resources may help with their selection, training, and supervision:

- Schneider, E.C., Altpeter, M., & Whitelaw, N. (2007). An innovative approach for building health promotion program capacity: A generic volunteer training curriculum. The Gerontologist, 47(3):398-403.
- Senior Corps. RSVP (2008). Senior Corps: A program of the corporation for national and community service. Available at http://www.seniorcorps.gov/about/programs/rsvp.asp.
- Kloseck, M., Crilly, R.G., & Mannell, R.C. (2006) Involving the community elderly in the planning and provision of health services: Predictors of volunteerism and leadership. Canadian Journal on Aging / La Revue canadienne du vieillissement; 25(1):77-91.
- Martinez, I.L., Frick, K., Glass, T.A., et al. (2006). Engaging older adults in high impact volunteering that enhances health: Recruitment and retention in the Experience Corps® Baltimore. Journal of Urban Health: Bulletin of the New York Academy of Medicine, 83(5):941-953.
- Morrow-Howell, N., Hinterlong, J., Rozario, P.A., & Tang, F. (2003). Effects of volunteering on the well-being of older adults. The Journal of Gerontology, 58B(3):S137-S145.
- Narushima, M. (2005) 'Payback time': Community volunteering among older adults as a transformative mechanism. Aging and Society, 25(4) 567-584.

Step 4: Form an advisory committee

REACH OUT is an evidence-based intervention adapted for use in communities. It is highly recommended that the intervention be implemented as designed with proper certification. However, deliberate planning is essential to make the intervention "work" in each setting. Forming an Advisory Committee is an effective way to involve key stakeholders in all aspects of this decision-making process, from beginning to end, and to forge strong and lasting relationships.

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The role of the Advisory Committee is to provide policy direction and oversight for the program's design, implementation, and evaluation. Such a committee can often be helpful in "opening doors," getting buy-in, advocating for needed resources, and promoting the program.

If you have opted to implement REACH OUT as an *individual agency*, the Advisory Committee will likely be comprised of the agency's director and the entire program team: program coordinator, case managers, clinical supervisor, evaluators, trainers, and any university partners. If the agency is small, the advisory committee may be able to include everyone involved in the program. If it is relatively large, you may need to select individuals who will informally "represent" others in the same role (e.g., one case manager to "represent" the other case managers, one supervisor to "represent" the other supervisors). In addition, if the implementation is on a broader scale in a *network of agencies* (Home Health Care system or AAAs), the Advisory Committee might also include the State Commissioner on Aging (or the equivalent within your state) and representatives of financial services and foundations.

- Determine which stakeholders you would like to invite to be on your Advisory Committee. Try to limit the group to a manageable size, between 6 and 10 members

- Meet face-to-face with each of the stakeholders to explain the program and invite them to join the Advisory Committee

- Once the commitee members have agreed to participate, convene the Advisory Committee at a suitable time and place. Plan the first few meetings thoughtfully to accomplish several tasks:

  - Educate on the program's goals, history, philosophy, and experience
  - Select a Chair, Co-chair, and Secretary
  - Agree on a regular meeting schedule, plan of work, and timeline
  - Discuss pertinent issues related to staffing, finance, training, etc.
  - Agree on any minor modifications to the REACH OUT program design.

Most likely, meeting often at first will be needed to determine the program's design and assure sufficient resources to carry it out. Later, a less frequent schedule will suffice to review progress and identify needed improvements or adaptations.

Step 5: Solidify the intervention design

The REACH OUT intervention is designed to improve the lives of dementia caregivers by reducing their stress and burden. This is done by increasing their knowledge of dementia and the caregiving role and by teaching them various skills targeted at themselves (improving their health, teaching stress management) and the care recipient (teaching them how to manage problem behaviors).

The basic REACH OUT program components, delivered throughout the course of the intervention, are described below. These components were adapted from those used in the REACH II clinical trial, modified for feasibility use within AAAs. If minor modifications are needed for use within the setting, involve the Advisory Committee in the decision (as mentioned in Step 4).

Risk Appraisal
On the first home visit, case managers conduct a risk appraisal designed to gather information to tailor interventions for the caregiver. The assessment consists of two parts:

- Collection of basic demographic information on the caregiver and the care recipient (age, gender, race, marital status, income, and general health) and identifying their relationship (e.g., spouses, parent-child).

- A formal Risk Appraisal based on REACH II asks caregivers about 16 common sources of stress and burden such as behavioral disturbances, presence of dangerous objects in the home, and level of caregiver depression. Responses help case managers decide how to balance their time to best address emergent and long-standing problems. Many of the items on the Risk Appraisal are used to assess outcomes of the intervention and are discussed further in Step 13.

> **❗ Tips for Case Managers: Using the Risk Appraisal**
>
> The critical problems that emerge from the Risk Appraisal help case managers structure future conversation, interventions, and referrals – but they are not the only source of information for these purposes. Equally important are the problems that caregivers believe are most urgent or serious, for whatever reason. It is often useful to ask the caregiver to rank problems by assigning "1" to the most urgent, "2" to the next most urgent, etc. Starting with the caregiver's #1 problem will build confidence, provide comfort, and reduce stress. Keep in mind that adjustments may be needed as circumstances evolve. Training, consultation with a supervisor, clinical judgment, and a heavy dose of flexibility will help you make the right decision. For example, it is not unusual for a case manager to prepare to discuss for a home visit on incontinence or repeated questioning, and discover that the more immediate issue is wandering.

Education about Dementia, Caregiving, and Stress
Case managers use the first visit to establish good rapport with caregivers and care recipients, begin sharing important information about dementia and the caregiving experience, and introduce tools and techniques for reducing caregiver burden. Sharing information may be one of the most important components of the program as many caregivers have little or no knowledge about dementia. This program provides a substantial amount of information to caregivers about the nature of dementia (e.g., progression, expected deficits), the caregiving role, stress associated with intensive caregiving, and the adverse effects of stress on the human body.

Caregiver Health
Highly stressed and burdened caregivers often neglect their own health in order to satisfy the needs of their care recipient. This sacrifice frequently affects the caregiver's ability to provide optimal care to their loved one. In this REACH OUT component, case managers teach caregivers how to use a resource, America's Health Guide for Seniors and Caregivers, commonly called the "Health Passport." This small booklet provides information about health maintenance activities (such as annual physical exams) and serves as a tool to record health information and health appointments. Care recipients often have a similar booklet to keep track of appointments, medical information, etc. The Health Passport can be purchased at: http://securitec.com/seniors-caregivers-health-guide.php.

Home Safety

With the caregiver's permission, the case manager tours the home to note any safety concerns in the physical environment. These might include such risks as the availability of weapons and sharp objects, excessive clutter, and types of shoes worn by the care recipient (e.g., rubber soles are preferable). At each subsequent contact, the case manager "checks in" to ascertain whether caregivers followed through with suggested changes.

> **❗ Tip for Case Managers: Checking Home Safety**
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> Caregivers may view the home safety check as criticism of their homemaking abilities. Tact, diplomacy, and empathy can calm the tension and allow the caregiver to accept (and follow) referrals for housecleaners, professional organizers, and other appropriate community resources.

Behavior Management

One of the major risk factors for placing a care recipient in an institution is behavioral disturbance. [20, 21, 22] To address this risk, case managers help caregivers gain proficiency in behavior management skills using the ABC approach, which emphasizes the placement of behavior management procedures within a problem solving rubric. Behavioral prescriptions are documented on a standard form that asks for specific definition of the problem, the goal of the prescription, strategies for preventing the behavior, and therapeutic responses when the problem occurs. Dozens of generic prescriptions are available from REACH II for behaviors such as wandering, aggression, and difficulty with personal hygiene. Discussing these prescriptions with caregivers will help identify how they need to be tailored to the specific needs of the dyad.

> **❗ Tips for Case Managers: Dealing with Sensitive Issues**
>
> Some of the questions posed to caregivers may raise sensitive issues or "touch a nerve." It often helps to establish good rapport before administering questionnaires, particularly before asking potentially sensitive questions. If possible, save them for the end of a visit.

Stress Management

Case managers help caregivers manage stress by using one of the many empirically supported stress reduction techniques. Three techniques commonly recommended are: breathing exercises

•For a repository of available behavioral prescriptions, see www.memphis.va.gov/reachva/index.asp.
•For a template that can be used by case managers to develop behavioral prescriptions, see Appendix A.

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("Signal Breath"), listening to music, and stretching exercises. Of these three, the Signal Breath technique is ideally suited to caregivers because it is easy to learn, can be applied in a matter of minutes, and can be used anywhere, at any time, and as often as needed. This simple technique is an effective calming device, when caregivers are in the middle of stressful situations and also just before they are about to interact or intervene with their care recipient. It comes in handy for case managers as well!

Step 6: Confirm the protocol

REACH II combined the Full Intervention components into nine home visits spread over six months. Visits were interspersed with three therapeutic telephone calls primarily for a check-in and reminder about the next visit, and to give caregivers a chance to ask any questions or share concerns. In addition, there were five structured telephone support group meetings.

REACH OUT originally modified this protocol to four home visits, supplemented by four phone calls, during a three to four month period. Although the REACH OUT study found this schedule of home visits and phone calls to be effective, the most recent adaptation recommends two further modifications. First, the recommended number of home visits is now increased to six sessions distributed over either sixteen or twenty-four weeks. Second, it is recommended that the year be divided into two phases: the Full Intervention Phase (sixteen or twenty-four weeks) followed by a Maintenance Phase lasting six to eight months.

In this adaptation, the same amount of caregiver training is provided over a longer period of time, yielding a less "rushed" training atmosphere. More important, the recommended protocol extends overall contact with caregivers and care recipients, and allows case managers more time to form a strong positive relationship with the dyads. Still, the frequency of contact is tailored to each caregiver, depending on need and interest.

For more information on Signal Breath Relaxation, see Appendix B.

Ultimately, the exact tailoring of the schedule sessions is up to you. However, be sure your ultimate protocol:

- Allows case managers to fully assess client's needs
- Provides time for in-depth responses when clients call with questions or problems
- Includes follow-up for continued support and guidance beyond the final scheduled visit
- Devotes adequate time to each visit (up to two hours)
- Allows time for caregivers to fully articulate the problems they are having with caregiving
- Assumes a reasonable amount of time to travel from one home to the next
- Includes some flexibility to accommodate vacations, holidays, and illness among caregivers, care recipients, and case managers.

❗ Tips for Case Managers: Leaving On Time

One of the more challenging and often heart-wrenching tasks is leaving a home on time so that you stay on schedule for subsequent visits and meetings. As relationships with caregivers and care recipients unfold, the temptation to linger and continue engaging conversations will grow. Prepare ahead of time for this by telling caregivers early in the visit when you must leave and practicing polite ways of saying goodbye.

Additional REACH II Components from Clinical Trial

REACH OUT does not include two intervention components from the original REACH II clinical trial protocol because the Advisory Committee thought it was not feasible to include them along with all of the other components and still deliver an effective program. These components, enhancement of social support and support groups, used specialized telephones with display screens linked to a computer integrated telephone system to provide information and facilitate group support conference calling.[16] They hold great promise as a medium for intervention delivery, particularly in states with large rural regions.

For more information on session schedules and Sample REACH OUT Protocols, see www.iog.umich.edu/reachout/reachout.htm and Appendix C.

Step 7: Plan for evaluation

Evaluating the program's effectiveness is vital to its continued existence, as a way to demonstrate its intrinsic value, justify current and future expenditures, and secure continued support. The first step in designing your evaluation is to define the outcomes you wish to achieve.

These outcomes are pertinent to caregivers . . .

- Reduced burden
- Less depression
- Fewer feelings of frustration toward care recipients
- Improved self-rated health
- Fewer sleep problems
- Satisfaction and acceptability of the program.

. . . while these relate to the care recipient

- Less likely to be left unsupervised
- Reduced wandering
- Less likely to have access to dangerous objects
- Improvement in behavior problems.

The evaluation methodology used in REACH OUT has been found to be feasible and is strongly recommended in its entirety. The evaluation instruments, described in Table 1, facilitate collection of data and monitoring of desired outcomes (see Step 13). If budget or staffing constraints make it difficult to implement the full evaluation, it is suggested that you omit an entire instrument rather than adjust its individual items.

*If your agency has a Client Enrollment Form, it may include some of the same information as required for the REACH Demographic Form. If so, transfer the relevant information from your Enrollment form to the REACH-specific form before making the first home visit to avoid asking duplicate questions.

**Other Risk Appraisals with 21 and 51 items are also available; however, these might not be feasible due to their length.

INSTRUMENT	PURPOSE	ITEMS	USE
Zarit Burden Screener (4-item screening tool)	To identify caregivers most likely to benefit from the intervention	4-item version of Zarit Burden Inventory, focused on the perception of stress and strain related to caregiving.[23] Using a 5-point scale for each item, combined scores must be 8 or higher to be eligible for enrollment in REACH OUT program	First home visit
REACH Demographic Form	To learn more about who is accessing your services and their particular situations, and to tailor your intervention in the future	Basic information on caregiver and care recipient (age, gender, race, marital status, relationship, income and general health*)	First and fourth home visit
Zarit Burden Scale (12- item measure)	To derive a subjective measure of caregiver burden and stress	12-item modified Zarit Burden Inventory.[24, 25] Caregivers are asked to respond to items which measure emotional and physical strain using a 5-point scale ranging from 0 (Never) to 4 (Nearly Always). Scores range from 0 to 44 with high scores indicating greater levels of subjective caregiver burden	Prior to first visit
Caregiver Questionnaire	To assess caregiver's perception of his/her health status and that of the care recipient	5 questions to assess self-reported health status and improvements in care recipient's memory, behavior, and mood	First and fourth home visit
Risk Appraisal	To assess individual risk factors of the caregiver	16 items to assess common sources of caregiver burden and strain**	First and fourth home visit
Satisfaction Questionnaire	To assess the satisfaction of caregivers and care recipients with program services	23 questions regarding satisfaction with types (i.e., specific components) and quality of service	Fourth home visit and at end of year
Depression Scale	To assess level of depression	9-item Patient Health Questionnaire (PHQ-9). Preferred by clinicians because of its lower literacy level, shorter length, title is more acceptable to caregivers who prefer language with less mental health stigma, and well validated in many previous aging studies as predictive of health outcomes	First home visit

Another evaluation tool for gathering qualitative evaluation information is a focus group. Consider convening a focus group of case managers from all sites for 1-2 hours to gather information on program effectiveness, ease of implementation, challenges, and suggested improvements. Focus groups are most successful when led by an independent, objective facilitator, and are guided by structured questions related to the overall experience, treatment model, strengths and weaknesses, and advice for changes.

To minimize bias, individuals collecting data using these forms should not be case managers. They might be other agency staff or perhaps university students helping out as part of a class or internship. It is best for the "evaluators" to accompany case managers on at least one home visit before administering the evaluation instruments, so that they are not complete strangers and will get more honest responses from the caregivers. If separating these two roles is not possible, case managers should receive additional formalized training in data collection and evaluation during the Case Manager workshop (see Step 9).

Step 8: Become familiar with Case Manager Training Manual and Caregiver Notebook

Individuals and agencies wishing to obtain UMDME certification will be given a Case Manager Training Manual and Caregiver Notebook. Although we believe that REACH OUT can be effective without these materials, their use will facilitate program implementation.

The Case Manager Training Manual offers a wealth of information and resources to guide the training session and provide a comprehensive orientation to the practical interventions that have been found to be highly effective in the REACH studies.

The Caregiver Notebook is a valuable resource that includes easily digestible information for caregivers on:

- Alzheimer's disease (and memory loss)
- Legal issues such as wills and estate planning
- Safety concerns
- Health considerations
- Caregiver well-being
- Caregiving challenges.

The Caregiver Notebook also includes information on: doctor-patient communication, advocacy with healthcare workers, bereavement, decision making regarding placement of the care recipient, and

material appropriate for young family members such as grandchildren and great-grandchildren to help them understand dementia.

Review both the Case Manager Training Manual and Caregiver Notebook carefully. If modifications were made to the intervention in Step 5, revise these documents accordingly. Take care to retain the same reading level and print size for the Caregiver Notebook because these have been tested extensively. Print copies and put them in 3-ring binders, with extra space for caregivers and families to add more information and resources as they become available.

A wealth of resources and tools are available for family members of all ages who are living with a loved one who has Alzheimer's disease or other forms of dementia.

> **! Tips for Case Managers: Expanding the Caregiver Notebook**
>
> Resist the temptation to initially add more material to the Caregiver Notebook. Instead, wait until specific questions and needs arise during home visits or phone calls. Then supplement the Notebook with articles and print material targeted toward the pressing concerns of the individual caregiver or family.

Step 9: Train case managers

A formal training workshop should be held to certify case managers before they begin seeing families. This workshop will either be conducted by the UMDME (http://www.iog.umich.edu/reachout/reachout.htm) or by a UMDME certified trainer. In either case, the workshop should cover several important topics:

- Brief Overview of REACH II clinical trial
- Introduction to the REACH OUT project
- Education about Alzheimer's disease and other dementias
- Risk appraisal/safety
- Health passport
- Relaxation training (Signal breath, music, and stretching)
- Behavior management (Behavioral prescriptions)
- Assessment.

For additional resources and websites on dementia and caregiving, see www.alz.org/index.asp, www.nia.nih.gov, and Appendix D.

To be most effective, training should emphasize active learning by encouraging questions, having workshop leaders model desired behaviors, and using participant role playing extensively. A typical workshop will last 1–1½ days (about 8–12 hours). Training should be repeated as new case managers are hired due to staff turnover or program expansion.

Case managers should receive complete copies of the Case Manager Training Manual and Caregiver Notebook at the workshop that can be used to plan and conduct their intervention sessions.

Periodic and regular refresher training (also known as recalibration) will help to ensure that case managers retain the skills learned in the initial training. Two strategies are recommended for this purpose:

- **Audio taping 'live' home visits**: Select at least two visits for each case manager and audiotape them as they occur. Ask the supervisor to review them for fidelity, and provide feedback on what went well and what could be improved. This strategy is ideal because it can capture actual performance shortly after certification. If the audiotape shows a serious problem, it can be addressed early through discussions between the case manager and the supervisor. The downsides of this method, however, are the need to obtain approval from the caregiver-care recipient dyad in advance and potential inhibited interactions during the home visit.

- **Retraining at 6-month intervals**: Bring case managers (and evaluators) back for a full-day session to refresh their skills, review any program changes, and address any bad habits that may be developing. Acknowledge the natural tendency to "drift" from required protocols as they get more comfortable with their roles, but emphasize the importance of high standards and continuous improvement. As part of refresher training, address these performance issues by asking case managers (and data gatherers) to role play an initial visit and an assessment, and then provide feedback to improve performance.

For training materials, see www.iog.umich.edu/reachout/reachout.htm.

"REACH OUT is one of the first successful translations of the seminal REACH II research program and an effective and valuable public health tool. This Action Guide will enable communities and agencies to implement this proven program with fidelity and make it widely available to family caregivers."

Richard C. Birkel, Ph.D. | Executive Director | Rosalynn Carter Institute for Caregiving John and Betty Pope Distinguished Chair in Caregiving | Georgia Southwestern State University

Section Three
MAKING IT HAPPEN

Step 10: Enroll caregivers

A variety of sources can be useful for identifying dyads (individuals with dementia and their caregivers) who may benefit from REACH OUT services:

- Current agency caseloads
- Intake records
- Waiting lists
- Referrals from home health organizations, hospitals, physicians, and case workers
- Recipient rosters for the Medicaid Elderly and Disabled Waiver
- Self-referral (e.g., families calling about respite services or financial assistance)
- Outreach at health fairs, nutrition centers, and senior centers
- Promotion through advertisements, flyers, brochures, newsletters, and websites.

Divide the list of potential participants among your case managers, striving to give case managers any clients in their current caseloads or other individuals with whom they are already familiar. Ask them to contact each caregiver (by phone or in person) to determine both interest in and eligibility for the program. A standard Screening Form can help to ensure that all the essential information is gathered and recorded, and is done so consistently for all potential caregivers. Some of the requested information on the Screening Form may have been obtained earlier when completing your state's required Caregiver Intake Form, particularly demographic information. If so, copy it onto the Screening Form prior to your interview so you can quickly confirm it without duplicating effort.

Using the results of the initial screen, identify those who are eligible for REACH OUT, that is, those who are caring for a family member with dementia and have a sufficient level of stress or burden to benefit from the intervention. Recommended criteria might include one or more of the following:

- The care recipient or the caregiver is over the age of 60.
- The care recipient lives in the community and receives care from a family member or fictive kin who lives in the home or the local area.

For sample Screening Form and Client Enrollment Form, see www.iog.umich.edu/reachout/reachout.htm.

- The caregiver is the "primary caregiver" defined as the family member or friend who spends the most time assisting or caring for the care recipient (e.g., preparing meals, dispensing medication, providing transportation). More than one family member can participate in the intervention, but the primary caregiver must participate in all sessions and all evaluation.
- The primary caregiver reports that a physician has diagnosed the care recipient with dementia, Alzheimer's disease, senility, or memory problems (formal confirmation of the diagnosis is not required).
- The primary caregiver scores 8 or higher on the 4-item Zarit Screener, indicating a significant burden associated with the caregiving role. The score is obtained by adding together the scores from each of the four items.

The list of eligible participants may be larger than can be served effectively. If so, consider narrowing the geographic area or reduce the number of agencies implementing the program. For those who are not accepted into the program, consider providing them with other resources or referrals—and keep them on a waiting list.

Obtain basic and non-identifying information on eligible clients who choose not to participate. This information can be extremely helpful in program assessment, to see who the program is and is not serving, whether it is reaching those most in need, and how it might expand the client base in the future. Include the city/location (if multiple cities/locations are used), gender, race and age of caregiver; gender, race and age of care recipient; their relationship; and reason for declining to participate in the program.

Step 11: Initiate intervention

Finally, it is time to begin delivering the REACH OUT intervention. Follow the protocol (from Step 6), assign caseloads to each case manager and provide support needed to arrange their first home visits.

> **"Many caregivers have not thought about the issues on the survey before, such as their own feelings about caregiving, their health, or how long they would be able to continue home care."**
>
> *- Case Manager*

MAKING IT HAPPEN

During the initial visit, the case manager will establish rapport with the caregiver and family members, describe the REACH OUT program, answer any questions, introduce the Caregiver Notebook, and conduct the risk appraisal.

As noted earlier, the information gathered from the Risk Appraisal will be used to identify the most salient caregiver problems and help determine the order in which intervention components are introduced during subsequent visits and phone calls. In addition, since the Caregiver Notebook is large and may be overwhelming, it should be introduced one section at a time. For example, in the first home visit the case manager might review the information on the first few pages covering Alzheimer's disease and memory loss. The second visit could then introduce another element, perhaps one pertaining to the caregiver's top priority concern.

❗ Tips for Case Managers: Anticipating Common Situations During Home Visits

- Be ready in the first visit for misunderstanding of what the intervention is about. Expect to hear comments like: "I thought this was a respite program" or "Why can't you come more often and take us to the doctor?"
- The caregiver may forget that you are coming and be totally "thrown" by your visit—or not be home. Bring a calendar or notepad on the first visit to leave for the caregiver, and record your next visit and any other important dates (e.g., medical appointments, home health visits, prescription refills).
- Caregivers may not remember the questions they want to ask you. Provide a notepad or index cards, and encourage them to write questions as they arise, both for you and for their healthcare providers.
- Don't be disappointed if you don't cover all you intended. Keep notes of what you accomplished and plan to pick up where you left off at the next visit.
- If home health services are needed, consult with the care recipient's physician to secure authorization so that the services will be covered by Medicare or other insurance.
- Older female caregivers may be more likely to show denial and to experience difficulty with the level of responsibility placed on them as caregivers. Offering them understanding for their difficult role and a high level of support can help address their anxiety and reduce stress.
- Families with more than one caregiver provide a unique challenge, adding another dimension of family dynamics to the interactions. Be flexible and sensitive to these dynamics and strive to meet with all caregivers concurrently.
- Adult children caring for a parent may be uncomfortable with changing diapers or bathing. Offer them empathy and help secure the services of another family member, friend, or home health agency.

Occasionally during a home visit, the case manager may encounter an urgent adverse event—something that must be addressed immediately—with either the caregiver or the care recipient. Some of these events, and suggested responses include:

- **Severe clinical depression:** Contact the family doctor and help secure an appointment as soon as possible.
- **Firearms present in the home:** Urge caregivers to remove firearms (store at the home of a relative or friend); separate the ammunition and store in a locked closet; call the local police and have them un-load and lock in the trunk of a car.
- **Extreme financial problems:** Initiate a referral for emergency financial assistance to cover the basic necessities of food, housing, utilities, etc.
- **Extreme agitation, aggression, or sudden change in behavior (e.g., stops eating):** Call the physician immediately to describe the symptoms and get instructions, then schedule an appointment as soon as possible.
- **Risk of harm to caregiver:** Call the physician and seek approval to call an ambulance for assistance (so the ride will be covered by Medicare).
- **Suspected abuse:** Contact the authorities (e.g., police, adult protective services) as required by law.
- **Family emergency (death, house burning, and job loss):** Put the intervention on hold and do your best to pick up when the emergency is resolved.

In a situation where either the caregiver or care recipient is a danger to him- or herself or others, including abuse or suspected abuse, licensed professionals (e.g., social workers, nurses, psychologists) are mandated by law to report these events. However, judgment must be used when contacting officials. States differ on the specifics of reporting. Licensed professionals are encouraged to familiarize themselves with State reporting laws.

In any of these circumstances, do not hide anything from the care recipient. Ask for permission first but make it clear that your primary concern is to protect his or her safety, privacy, and confidentiality. If necessary, it is recommended to encourage the caregiver to contact a physician or the authorities, or to obtain permission from the caregiver for the case manager to contact the physician or authorities.

During the fourth home visit, be sure to plan for follow-up and continued support during the Maintenance Phase. Ask the caregiver to complete a Maintenance Plan Worksheet, either independently or with help, to identify what they found most helpful from the intervention, strategies they have been using with their care recipient, and names and numbers of people they can call for support or help.

For a sample Maintenance Plan Worksheet, see Appendix E.

Step 12: Support and supervise case managers

The role of a case manager is challenging and requires flexibility, creativity, strong communication, and problem solving skills. Support and technical assistance from the program coordinator, supervisors, and other expert resources is essential to maintain program integrity, quality, and effectiveness. Some supportive strategies include:

• Weekly case conference reviews, led or facilitated by someone who is very familiar with the REACH OUT intervention on an in-depth level. These should be conducted face-to-face, and allow case managers to share information and receive advice on their cases.

• A telephone hotline available to case managers during specific scheduled times, preferably two half-days per week, when one or more experts would be available to discuss unusual or difficult cases. Such experts could be the REACH OUT program coordinator or personnel from the University of Michigan, Institute of Gerontology (UMIOG).

• If implementing the intervention in multiple sites, monthly conference calls with case managers (and perhaps the full Advisory Committee) to discuss overall program status, progress, challenges, and needed program modifications.

"This Action Guide will allow community agencies to implement a strong program to help family caregivers of people with Alzheimer's disease and other dementias. Programs like this should be available to every family caregiver across our country because they can help the caregiver to provide the best possible assistance for the person with Alzheimer's or other dementia while also reducing the burden of caregiving and maintaining the caregiver's own health and well being."

Katie Maslow | Associate Director for Quality Care Advocacy | Alzheimer's Association

Step 13: Track program implementation

As implementation progresses, the Program Coordinator should closely monitor program activities as well as outcomes.

Activities

- **Track activities and progress of each caregiver and family**
  Documenting home visits, phone calls, and the treatment components provided in each, will help case managers stay "on top" of the case, assure consistency and fidelity of the REACH OUT intervention, and provide a historical record. The Schedule of Treatment Form is a sample document for case managers to record the number of home visits and therapeutic phone calls. It also lists all treatment components to be "checked off" if used during a visit and thus serves a dual purpose to help ensure participants receive all aspects of the intervention within a consistent timeframe.

- **Track all caregivers and families**
  Use a large calendar or spreadsheet to easily see all of the clients and the full caseload. Pencil in projected visit and phone call dates, and then write over them in ink when they actually occur.

- **Track overall REACH OUT participation and attrition**
  Because clients will not all be on the same schedule, an overall Client Tracking Form can display at a glance where each client is in the intervention (e.g., Week 4, Second Home Visit; Week 10: Phone Call). This form could also be used to note any comments about delays in scheduling or attrition due to, for example, a move to another city or state, hospitalization, a nursing home admission, or death.

Outcome

Outcome measures of both effectiveness and extent of treatment implementation include:

- Caregiver stress, burden, and emotional well-being (using the Zarit Burden Scale)
- Perceived change in caregiver health (using the Caregiver Questionnaire)
- Extent of improvement in care recipient memory, mood and behavior problems, and risk behaviors (using the Risk Appraisal)[20]

For sample Schedule of Treatment Form, see www.iog.umich.edu/reachout/reachout.htm.
For sample Client Tracking Form, see www.iog.umich.edu/reachout/reachout.htm.

- Caregiver implementation of the therapeutic procedures (using Treatment Fidelity Form)
- Both caregiver and agency staff satisfaction with the program (using Satisfaction Survey; if possible, the Satisfaction Survey should also be administered for those caregivers who drop out of the program early for any reason).

Step 14: Sustain program over long term

Once the program is fully operational and the major "kinks" have been worked out, invest some time and energy into exploring ways to guarantee that the intervention can be sustained for years to come. Some avenues to pursue might include the following:

- Make a strong commitment to continuous improvement. Adopt a management philosophy and organizational process that engages your staff in identifying, planning and implementing ongoing improvements in REACH OUT intervention service delivery.
- Brief all staff in your agency or network including Advisory Committees and Boards of Directors. Do so early in the implementation phase so that they are aware of this exciting, innovative initiative, and then keep them updated on assessment and evaluation results through presentations, emails, newsletters, etc.
- Spread good news by "talking up" the program with colleagues at the water cooler, in the break room, during short luncheon brown bags, etc.
- Expand to other agencies, networks, neighboring counties, or regions. Offer to train their staff and provide opportunities to shadow experienced case managers on home visits. Consider training sessions that combine refresher experiences for current staff with initial training for those newly hired.
- Promote the program through newsletters, flyers, websites, presentations at conferences and meetings, health fairs at senior centers, etc. Share both positive and negative outcomes, since the full picture will help others understand the benefits and the challenges.
- Incorporate the REACH OUT intervention into existing ongoing programs.
- Seek additional sources of funding from foundations or other philanthropic organizations.
- Establish streamlined billing options and reimbursement mechanisms.

For forms and procedures for outcome evaluation, see Table 1 in Step 6 and visit www.iog.umich.edu/reachout/reachout.htm. Note that some of the instruments are used initially for clinical assessment and again later on to measure outcomes.

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Additional Resources

Websites

Administration on Aging
www.aoa.gov
www.eldercare.gov
www.aoa.gov/prof/aoaprog/caregiver/careprof/
   resources/caregiver_resources.aspx
www.aoa.gov/prof/aoaprog/caregiver/caregiver.aspx

Alliance for Aging Research
www.agingresearch.org

Alzheimer's Association
www.alz.org

**Alzheimer's Disease Education
& Referral Center (ADEAR)**
www.alzheimers.org

Alzheimer's Foundation of America
www.alzfdn.org

Alzheimer's Research Forum
www.alzforum.org

American Health Assistance Foundation
www.ahaf.org/alzheimers

AARP
www.aarp.org/caregiving

American Red Cross Family Caregiver Program
www.redcross.org/services/hss/care/family.html

Banner Health Alzheimer's Institute
www.BannerHealth.com/_Alzheimers

Caregiver Bill of Rights
www.caregiver.com/articles/caregiver/
   caregiver_bill_of_rights.htm

Caregiver Stress Check
www.alz.org/stresscheck/overview.asp

Caregiver Tip Sheet
www.aoa.gov/prof/aoaprog/caregiver/overview/docs/
   CaregiverTipSheet.pdf

**Caregivers Count Too! An Online Toolkit to Help
Practitioners Assess the Needs of Family Caregivers**
www.caregiver.org/caregiver/jsp/content_node.
   jsp?nodeid=1695

Caregiving in the U.S.
www.aarp.org/research/reference/publicopinions/
   aresearch-import-853.html

Caring Connections (Advance Care)
www.caringinfo.org

Centers for Disease Control and Prevention
www.cdc.gov/alzheimers
www.cdc.gov/aging

Dementia Guide
www.DementiaGuide.com

Family Caregiver Alliance
www.caregiver.org

Family Caregiving
www.redcross.org/services/hss/care/family.html

Family Caregiver Support – State Facts at a Glance
www.aoa.gov/PROF/aoaprog/caregiver/careprof/
    resources/fcs.pdf

Fisher Center for Alzheimer's Research Foundation
www.alzinfo.org

Health Passport
http://securitec.com/seniors-caregivers-health-guide.php

Inspire
www.inspire.com

Institute of Medicine
www.iom.edu

Mayo Clinic
www.mayoclinic.com

Medicare
www.medicare.gov/Caregivers

MedlinePlus
www.nlm.nih.gov/medlineplus/alzheimersdisease.html

National Alliance for Caregiving
www.caregiving.org

National Institutes of Health
www.nia.nih.gov/alzheimers
www.nia.nih.gov
www.clinicaltrials.gov
www.ninds.nih.gov

Rosalyn Carter Institute on Caregiving's Evidence-Based Caregiver Intervention Resource Center
www.rosalynncarter.org/dynamic_grid

Books and Articles

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Appendix A

Specific behavior:

Overall goal of this prescription:

Please remember that dealing with behavior problems can be stressful. The brief relaxation strategies will help you deal with stress when dealing with this problem. In particular, we recommend using the signal breath technique immediately before you use the strategies suggested in this behavioral prescription.

Strategies for preventing a behavior problem from occurring:

Strategies for guiding how you respond during <u>or</u> after a problem behavior occurs:

General Information:

You are a dedicated caregiver and you are doing a great job. We understand that this problem can be very upsetting to you and are committed to helping you with this problem. We believe these strategies will help and look forward to working with you in the coming weeks. Please contact your case manager _____Name_____ if you have any questions or concerns.

Appendix B
SIGNAL BREATH RELAXATION

Introducing Signal Breath Relaxation

The tasks and burdens associated with Caregiving are typically numerous and varied and often change across the course of the dementing illness. Given these often overwhelming responsibilities, caregiving for family members with dementia is often associated with frustration or stress which can potentially lead to reduced health and well-being. However, people <u>can</u> learn to relax, even in stressful situations.

Deep breathing techniques helps to circulate more oxygen throughout the body. Deep breathing has been shown to increase alertness and reduce the effects of stress. The Signal Breath technique is easy to learn. It was specifically designed to use in the middle of a stressful situation. Since we know caregivers do not have a lot of time, the great thing about the signal breath is that it only takes a few moments and can potentially reduce a lot of tension.

Ask caregiver:
"What sort of caregiving situations have been frustrating or stressful to you?" (Have caregiver name a couple of problems that have recently come up during caregiving).

_____

_____

_____

To help you reduce your stress and tension in situations like these, we are going to practice a relaxation strategy called Signal Breath. I encourage you to use this strategy on a daily basis. Our goal in practicing is to help you gain more control over your tension so that you can manage stressful situations better.

Rating Your Level of Tension or Stress

It is very helpful to learn to rate your level of tension or stress both before and after the exercise.

Let's begin by rating your level of tension before the practice exercise using a scale of 1 to 5 (5 being the highest). I will also ask you to re-rate your level of tension after the exercise. What number/phrase best represents your current level of tension? Before the relaxation exercise, I feel _____ (Rate from 1 to 5).

Instructions for Signal Breath

The Signal Breath was designed specifically to help you when you are in the middle of stressful situations. We chose this simple but effective technique, because caregivers often have limited time for themselves. The great thing about the Signal Breath is that it only takes a moment and can potentially reduce a lot of tension. Also, it can be used anywhere, at any time, as many times as you want. In fact, you could even use the Signal Breath in a crowded room and no one would know.

>   **1.** Okay, so let's try this out. I want you to take in a deep breath, and hold it for a few moments. However, don't breathe so deeply or hold it so long that it is uncomfortable. About 3 or 4 seconds is usually long enough. Exhale slowly while at the same time saying calming words such as "relax," "let go," or "easy does it" to yourself. Also, while you are exhaling, try to let your jaw, shoulders, and arms go loose and limp.

>   **2.** Okay, let's try it again. Take in a deep breath, and hold it. Now, let it go slowly and say to yourself a calming word. Let your jaw, shoulders, and arms go loose and limp.

>   **3.** One more time, take in a deep breath and hold it. Let it out slowly. Relax. Let your body go loose and limp. Now let's re-rate your level of tension. What number/phrase best represents your current level of tension?

After the Signal Breath exercise, I feel _____ (Rate from 1 to 5).

Ask Caregiver: *"How did that feel for you?"*   _____

"Did it help a little?"   _____

"What was your relaxing word?"   _____

> **Note:** If caregiver says it didn't work or it was not helpful, remind them that it requires regular practice, and encourage them to do so.

Signal Breath Homework
I encourage you to practice the Signal Breath at least once each day. Some caregivers find it useful to practice when they are not stressed, because it helps reduce feelings of tension when stressful situations ultimately arise. That is great, but I also want you to practice it when you are in the midst of a stressful situation if possible.

Periodic Follow-up
At each contact, it will be important to "check in" with caregivers regarding their use of the Signal Breath and to note if they find it beneficial. Encourage caregivers to practice Signal Breath at least daily and at any other time that they are feeling stressed or overwhelmed.

Appendix C
SAMPLE REACH OUT PROTOCOL

The year-long protocol recommended for delivering the REACH OUT intervention consists of home visits and phone calls divided into a Full Intervention Phase, followed by a longer Maintenance Phase. One of the recommended options has six visits over six months, followed by two additional home visits over the next six months.

Full Intervention Phase: Six home visits over six months
Visit 1 at week 1
Visit 2 at week 4
Visit 3 at week 8
Visit 4 at week 13
Visit 5 at week 18
Visit 6 at week 24

Maintenance Phase: Two additional home visits over next 6 months
Visit 7 at week 38
Visit 8 at week 52

WEEK	HOME VISIT	PHONE CALL	ACTIVITIES
FULL INTERVENTION PHASE			
1	#1		1. Introduce and establish rapport 2. Describe the Program 3. Administer questionnaires: a. Client Intake Form b. Risk Assessment c. Caregiver Questionnaire 4. Gather information about difficult behaviors of patient 5. Introduce Caregiver Notebook 6. Provide education about Alzheimer's disease, caregiving, and stress (refer to Caregiver Notebook) 7. Conduct safety walk-through of home – (Caregiver Notebook)
4	#2		1. Follow up on Safety 2. Provide education about grief/loss and communicating with physicians (Caregiver Notebook) 3. Introduce Signal Breath relaxation (Caregiver Notebook) 4. Introduce Behavioral Prescription #1
6/7		#1	1. Follow up on Safety 2. Follow up on Signal Breath 3. Clarify details of Behavioral Prescription #1

WEEK	HOME VISIT	PHONE CALL	ACTIVITIES
8	#3		1. Continue to monitor Safety 2. Follow up on Signal Breath 3. Introduce Health Passport (Caregiver Notebook) 4. Follow up on Behavioral Prescription #1
11		#2	1. Continue to monitor Safety 2. Follow up on Signal Breath 3. Follow up on Health Passport 4. Follow up on Behavioral Prescription #1
13	#4		1. Continue to monitor Safety 2. Follow up on Signal Breath 3. Follow up on Health Passport 4. Follow up on Behavioral Prescription #1 5. Introduce Behavioral Prescription #2
15		#3	1. Continue to monitor Safety 2. Follow up on Signal Breath 3. Follow up on Health Passport 4. Follow up on Behavioral Prescription #1 5. Follow up on Behavioral Prescription #2
18	#5		1. Continue to monitor Safety 2. Follow up on Signal Breath 3. Follow up on Health Passport 4. Follow up on Behavioral Prescription #1 5. Follow up on Behavioral Prescription #2
21/22		#4	1. Continue to monitor Safety 2. Follow up on Signal Breath 3. Follow up on Health Passport 4. Follow up on Behavioral Prescription #1 5. Follow up on Behavioral Prescription #2
24	#6		1. Overview of Program (Safety, Signal Breath, Health Passport, Behavioral Prescriptions) 2. Provide Maintenance Plan 3. Administer Questionnaires: a. Risk Assessment b. Caregiver Questionnaire c. Satisfaction Survey d. Others required by your program

SAMPLE REACH OUT PROTOCOL

WEEK	HOME VISIT	PHONE CALL	ACTIVITIES
MAINTENANCE PHASE			

31		#5	1. Ask about general welfare
			2. Follow up on adherence to maintenance plan including
			   a. Safety concerns
			   b. Signal Breath
			   c. Health Passport
			   d. Behavioral Prescriptions
			   e. Use of support network

38	#7		1. Ask about general welfare
			2. Follow up on adherence to maintenance plan including
			   a. Safety concerns
			   b. Signal Breath
			   c. Health Passport
			   d. Behavioral Prescriptions
			   e. Use of support network
			3. Follow-up questionnaires (optional)

45		#6	1. Ask about general welfare
			2. Follow up on adherence to maintenance plan including
			   f. Safety concerns
			   g. Signal Breath
			   h. Health Passport
			   i. Behavioral Prescriptions
			   j. Use of support network

52	#8		1. Ask about general welfare
			2. Follow up on adherence to maintenance plan including
			   k. Safety concerns
			   l. Signal Breath
			   m. Health Passport
			   n. Behavioral Prescriptions
			   o. Use of support network
			3. Follow-up questionnaires (optional)

Appendix D
MAINTENANCE PLAN WORKSHEET

The things I found most helpful are

_____   _____

_____   _____

_____   _____

Remember the strategies that you and your case manager have used to address your family member's behavior.

When _____ happens, I will_____

_____

People I can call for suport or assistance

NAME:	NUMBER:
NAME:	NUMBER:

- Remember to use the Signal Breath Relaxation regularly, especially in stressful situations.
- Keep this manual and other educational materials available for you to refer to when needed.

Your case manager will call you 2 months after your completion of this program. This follow-up phone call will be an opportunity to talk about ways to continue to follow this plan by using the skills and information you have learned in the program.

Glossary

Action guide: a tool used to assist organizations in implementing intervention programs.

Area Agency on Aging (AAA): community agencies, funded by the States and the Administration on Aging (AOA), which provide services to older adults.

Behavioral disturbance: behaviors, usually outside the parameters of societal norms in a given setting, that are disturbing or burdensome to other individuals.

Behavior management: behavior management procedures assume that most behavioral disturbances are affected by antecedents (events preceding a behavior) and consequences (events following a behavioral disturbance). Behavior management procedures change the existing antecedents or consequence such that the problem behavior is less likely to occur.

Behavioral prescription: a written document detailing specific steps one (e.g., a caregiver) can take to change an environmental event preceding or following a behavioral disturbance to decrease its occurrence or severity.

Burden: any event in the caregiving situation that is considered troubling to the caregiver and affects his/her ability to provide optimal care to the care recipient.

Case managers: interventionists responsible for applying an intervention in "real-life" settings.

Clinical trial: the most rigorous experimental design to assess the effects of an intervention. Clinical trials usually include a control or comparison group, and follow very precise procedures accepted universally by the science community (e.g., random assignment to group). Because of its control and precision, the process of translation is often necessary before an intervention developed through a clinical trial is feasible for use in the community.

Evaluator (assessor): administers assessments before and after application of an intervention

Evidence-based intervention or program: refers to both biomedical and psychosocial treatments supported by systematic and highly rigorous empirical research.

Focus group: a form of qualitative research in which a group of people all asked about their attitudes towards a service or intervention.

Health Passport: a commercially available tool used by the caregiver, and shared with the physician, for keeping a record of symptoms, medical services received, basic health information, and medications.

Interventionist drift: a well-documented phenomenon wherein individuals trained to apply an intervention to criterion become less precise (drift) in the application of the intervention over time.

Medicaid Elderly and Disabled Waiver: provides an alternative to nursing home care for eligible older persons and adults with physical disabilities.

Program coordinator: a person responsible for overall coordination and management of program planning, implementation, and evaluation.

Qualitative empirical evidence: non-numerical empirical evidence collected through face-to-face meetings and observations.

RE-AIM: a model designed to guide researchers, practitioners, and policy makers when testing a translated intervention in a community setting.

REACH I (Resources for Enhancing Alzheimer's Caregiver Health): a National Institutes of Health (NIH)-funded cooperative agreement wherein six intervention sites tested different Alzheimer caregiver interventions to ascertain which types of interventions are most efficacious.

REACH II: a NIH-funded follow-up study to REACH that took the findings from the various REACH I interventions and designed a single intervention for Alzheimer's caregivers. This intervention was evaluated through a randomized multi site clinical trial.

REACH OUT: an AOA-funded translation trial that used procedures from community based participatory research to devise a feasible REACH-like intervention for use in AAAs.

Readiness: the degree of preparedness of an agency to implement an intervention.

Recalibration: the assessment of an interventionist's performance of an intervention during a trial. If interventionist drift is detected, he or she is retrained to the original criteria.

Risk appraisal: as used in the REACH trials, a screening tool used to identify and prioritize existing dyadic problems contributing to stress and burden.

Social support: physical and emotional comfort given to us by our family, friends, coworkers and others.

Stakeholder: a person, group, organization, or system that affects or can be affected by an organization's actions.

Supervisor: a person responsible for clinical oversight and support within a social service agency.

Trainer: responsible for designing, conducting and evaluating interventionist certification to implementing an intervention.