



# TRANSLATING INNOVATION TO IMPACT:

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

Thursday, June 28, 2012 | Grand Hyatt Washington, DC | 1000 H Street, NW

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# TABLE OF CONTENTS

---

AGENDA..... 2

PROGRAM OVERVIEWS..... 4

SPEAKERS..... 17

ATTENDEES..... 20



# AGENDA

## OBJECTIVES

**1** Highlight models (programs) that have been brought to scale to support individuals with Alzheimer's disease and their caregivers—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.

**2** Discuss models that did not translate well—exploring what implementation issues they faced and the lessons that can be learned from these models.

**3** 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**

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, MPH, MSW**

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**

Minnesota-North Dakota Alzheimer's Association

9:45 a.m.

#### Multi-Modal Community Based Program for Persons with MCI or Early-Stage Dementia

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

University of Illinois, Urbana Campus

9:50 a.m.

#### Panel discussion

**Shannon Skowronski, MPH, MSW**

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, MA**

Administration on Aging  
Administration for Community Living

11:50 p.m.

#### NYU Caregiver Intervention

**Mary Mittelman, DrPH**

NYU Comprehensive Center on  
Brain Aging

12:00 p.m.

#### Panel discussion

**Greg Case, MA**

Administration on Aging  
Administration for Community Living  
(Moderator)

11:45 a.m.

#### Skills<sub>2</sub>Care™

**Laura Gitlin, PhD**

Johns Hopkins University  
Center for Innovative Care in Aging

11:55 p.m.

#### REACH II and Cleveland Managed Care

**Leisa Easom, PhD, RN**

Georgia Southwestern State University  
Rosalynn Carter Institute for Caregiving

12:45 p.m.

#### Open discussion

1:35 p.m.

#### Lunch

## SESSION 3

### CARE COORDINATION AND CARE TRANSITIONS

2:35 p.m.

#### Session Introduction

**Jane Tilly, DrPH**

Office of the Assistant Secretary for  
Planning and Evaluation, HHS

2:50 p.m.

#### Collaborative Care Model for Alzheimer's Disease and Related Dementias

**Christopher Callahan, MD**

Indiana University  
Center for Aging Research

2:40 p.m.

#### Partners in Dementia Care and Care Consultation

**David Bass, PhD**

Margaret Blenkner Research Institute  
Benjamin Rose Institute on Aging

2:55 p.m.

#### Panel discussion

**Jane Tilly, DrPH**

Office of the Assistant Secretary  
for Planning and Evaluation, HHS  
(Moderator)

2:45 p.m.

#### Transitional Care Model for Cognitively Impaired Elders

**Karen Hirschman, PhD, MSW**

University of Pennsylvania  
School of Nursing

3:40 p.m.

#### Open discussion

## CLOSING

4:30 p.m.

#### Closing remarks

**Susan Peschin**

Chief Operating Officer  
Alliance for Aging Research

5:00 p.m.

#### Meeting adjourns

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# PROGRAM OVERVIEWS

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## SESSION 1: INTERVENTIONS TO ASSIST INDIVIDUALS WITH DEMENTIA

Reducing Disability in Alzheimer’s Disease (RDAD) .....	13
Susan McCurry, PhD	
The Early Identification and Support Project .....	6
Michelle Barclay	
Multi-Modal Community Based Program for Persons .....	9
with MCI or Early-Stage Dementia	
Sandra Burgener, PhD, APRN-BC, FAAN	

## SESSION 2: INTERVENTIONS TO ASSIST THE FAMILY CAREGIVER

Skills <sub>2</sub> Care™ .....	14
Laura Gitlin, PhD	
NYU Caregiver Intervention .....	10
Mary Mittelman, DrPH	
REACH II and Cleveland Managed Care	
<i>GA Care Consultation (Translation of Cleveland Managed Care)</i> .....	7
<i>GA REACH (Translation REACH II/REACH VA)</i> .....	8
Leisa Easom, PhD, RN	

## SESSION 3: CARE COORDINATION AND CARE TRANSITIONS

Partners in Dementia Care and Care Consultation .....	11
David Bass, PhD	
Transitional Care Model for Cognitively Impaired Elders .....	15
Karen Hirschman, PhD, MSW	
Collaborative Care Model for Alzheimer’s Disease .....	5
and Related Dementias	
Christopher Callahan, MD	

# COLLABORATIVE CARE MODEL FOR ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

## 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

## References

- Callahan CM, Boustani MA, Weiner M, et al. (2011) Implementing dementia care models in primary care settings: The Aging Brain Care Medical Home. *Aging & Mental Health* 15: 5-12.
- Boustani MA, Sachs GA, Alder CA, et al. (2011) Implementing innovative models of dementia care: The Healthy Aging Brain Center. *Aging & Mental Health* 15: 13-22.
- Callahan CM, Boustani M, Sachs GA, Hendrie HC (2009) Integrating care for older adults with cognitive impairment. *Curr Alzheimer Res* 6: 368-374.
- Callahan CM, Boustani MA, Unverzagt FW, et al. (2006) Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized trial. *JAMA* 295: 2148-2157. ■



## PROGRAM OVERVIEWS (CONTINUED)

### THE EARLY IDENTIFICATION AND SUPPORT PROJECT

#### 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),

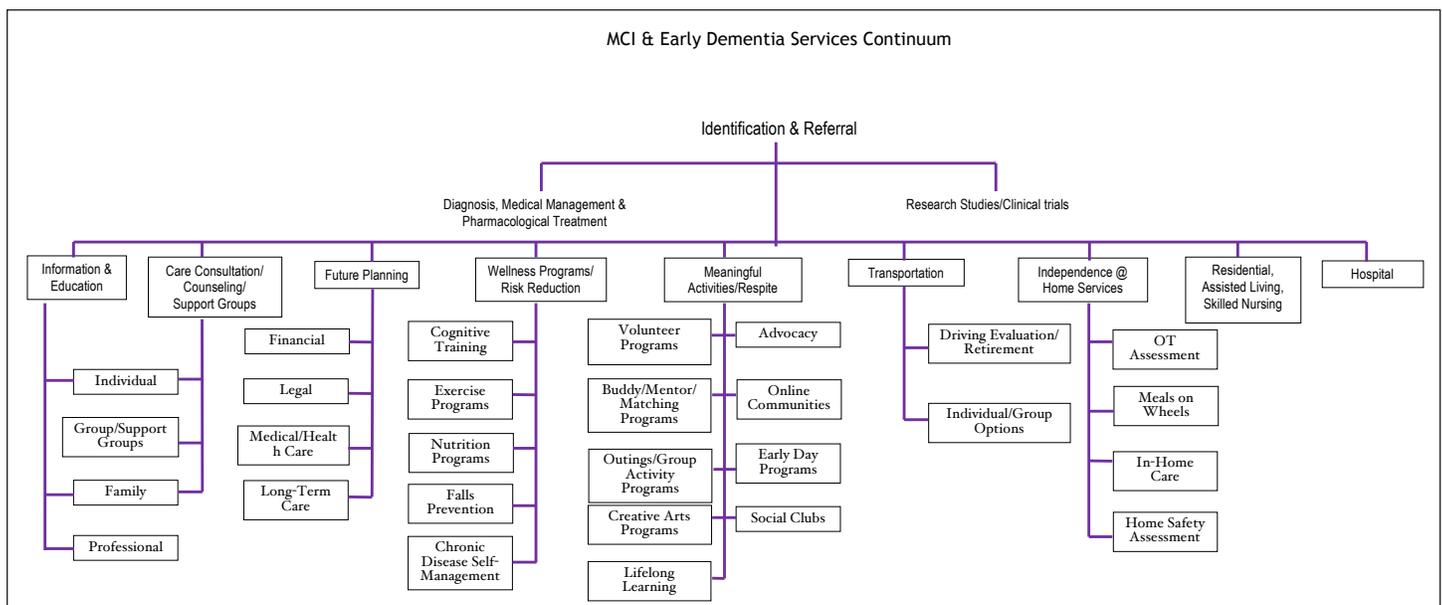
and peer support (trained mentors call newly diagnosed people with early dementia, invite them to meet-up gatherings, and provide social support). A preliminary evaluation was conducted as part of a National Alzheimer's Association social engagement pilot project.

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\\_e-book\(1\).pdf](http://www.alz.org/mnnd/documents/2010_taking_action_e-book(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)) ■

## GA CARE CONSULTATION (TRANSLATION OF CLEVELAND MANAGED CARE)

### 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)



## PROGRAM OVERVIEWS (CONTINUED)

- 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)

### 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

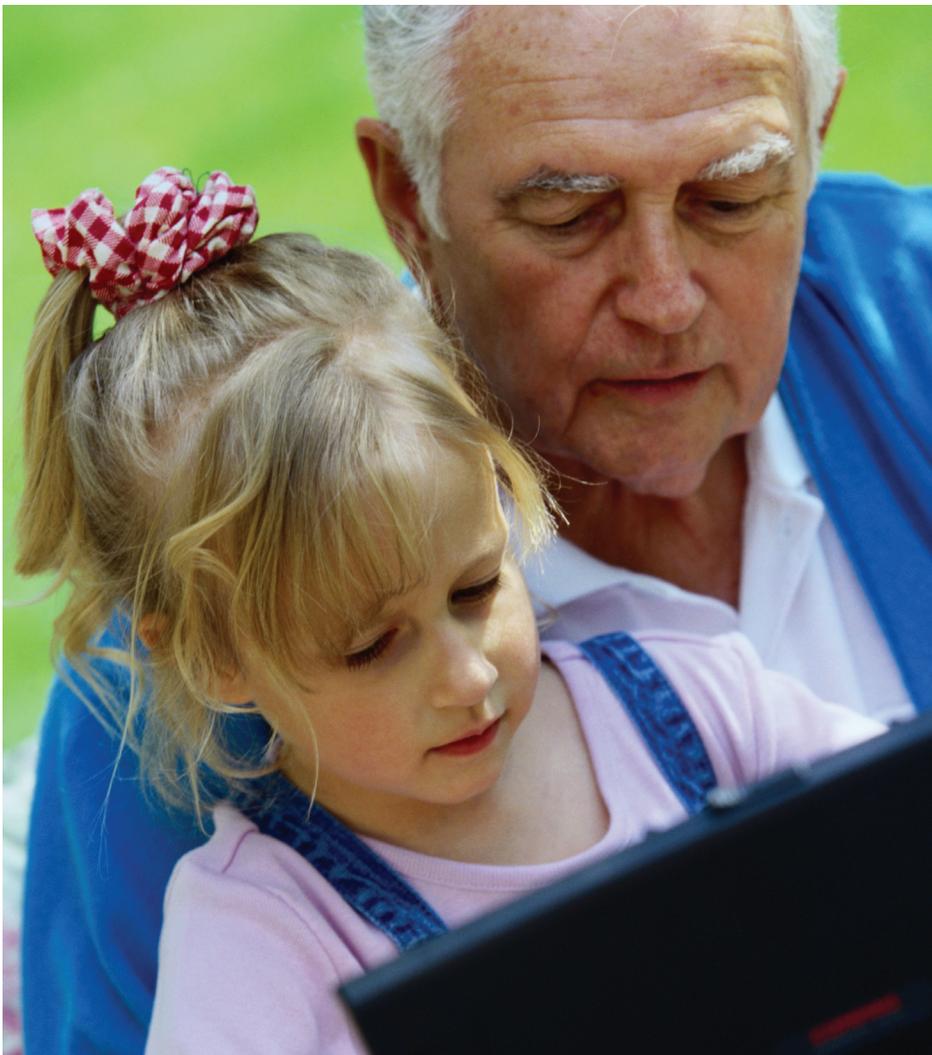
Caregivers providing care for an individual with Alzheimer’s disease for at least 4 hours/day with reported distress associated with such caregiving.

### 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. ■

## MULTI-MODAL COMMUNITY BASED PROGRAM FOR PERSONS WITH MCI OR EARLY-STAGE DEMENTIA

### 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 (TaiChi and QiGong), 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 TaiChi 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.

## PROGRAM OVERVIEWS (CONTINUED)

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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. ■

## NYU CAREGIVER INTERVENTION

### 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. ■

## PARTNERS IN DEMENTIA CARE AND CARE CONSULTATION

### 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;



## PROGRAM OVERVIEWS (CONTINUED)

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- 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, and
  - 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. ■

## REDUCING DISABILITY IN ALZHEIMER'S DISEASE (RDAD)

### 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, 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

## PROGRAM OVERVIEWS (CONTINUED)

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'. ■

### SKILLS<sub>2</sub>CARE™

*A Program Provided by Jefferson Elder Care at Thomas Jefferson University*

#### Description

Skills<sub>2</sub>Care™ 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 Skills<sub>2</sub>Care™ 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 Skills<sub>2</sub>Care™.

#### 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

Skills<sub>2</sub>Care™ 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 Skills<sub>2</sub>Care™.

### 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

Skills<sub>2</sub>Care™ 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-trainer's program also limits scalability.

### Successful Innovations

Skills<sub>2</sub>Care™ 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. ■

## TRANSITIONAL CARE MODEL FOR COGNITIVELY IMPAIRED ELDER

[www.transitionalcare.info](http://www.transitionalcare.info)

### 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<sup>1,2,3</sup> with cognitively intact older adults and one trial<sup>4</sup> 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 TCN 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 co-existing 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,<sup>5</sup> the Penn team formed partnerships with leaders of the Aetna Corporation (Aetna)<sup>6,7</sup> and Kaiser Permanente Health Plan (KP) to translate and integrate the

## PROGRAM OVERVIEWS (CONTINUED)

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TCM for use in everyday practice and 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 rehospitalizations 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.<sup>8</sup> 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.<sup>9</sup> 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.<sup>10</sup> 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.

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# SPEAKERS

## MICHELLE BARCLAY, MA



Michelle Barclay is the Vice President of Program Services at the Alzheimer's Association Minnesota-North Dakota. She received her Master's

degree in Developmental Psychology with a specialization in Gerontology from Louisiana State University. Michelle has worked with persons with dementia and their care partners for 20 years as a researcher, consultant, educator, and program planner. Her areas of expertise include early intervention and improving health care quality for people with dementia. She is the recipient of the Archstone Foundation Award for Excellence in Program Innovation for her work on the Partnering with Your Doctor program, and is a frequent presenter at the state and national level.

## DAVID M. BASS, PHD



David M. Bass, Ph.D. is the Vice President for Research and Senior Research Scientist at the Margaret Blenkner Research Institute of

Benjamin Rose Institute on Aging (BRIA). He became Vice President for Research at BRIA and Director of the nationally and internationally known Blenkner Research Institute in 2001. Dr. Bass served as the principal or co-principal investigator for more than 60 funded projects that investigated topics such as formal services and informal supports, caregiving for chronic illnesses, training health and social service professionals, bereavement, and elder abuse and neglect. A number of his recent projects focus on developing, testing, and broad-scale implementation of evidence-based programs, such as Care Consultation, Partners in Dementia Care, and Reducing

Disability in Alzheimer's Disease. Results from his research have been published in over 60 articles in scientific journals, including two in the 2010 special issue of the journal *Generations* on evidence-based programs. He also served as the guest editor of this special issue.

## SANDY BURGNER, PHD, APRN-BC, FAAN

Dr. Burgener is an associate professor at the University of Illinois at Chicago, and a gerontological nurse practitioner. Her main research area for the past 20 years has been the examination of variables associated with quality-of-life in persons with dementia (PWD). Dr. Burgener has conducted 8 studies in this area since 1987. Dr. Burgener's previous work has included the examination of a variety of personal, environmental, and caregiver-related variables associated with productive, positive outcomes in PWD. Her most recent NIH-funded research was a randomized trial of a three-part intervention specifically for persons with dementia. This pilot study follows her 6-year longitudinal study examining predictors of quality-of-life outcomes as PWDs move through the various disease stages. To facilitate knowledge-driven practice, Dr. Burgener also completed a study of more than 350 inner-city older adults (age 50) to determine the incidence and effectiveness of management of common chronic illnesses, including diabetes, hypertension, and depression. Dr. Burgener has more than 40 publications in a variety of prestigious nursing and multidisciplinary journals, including the *Journals of Gerontology*; *Image*; *Journal of Nursing Scholarship*; *Research in Nursing & Health*; *Journal of Alzheimer's Disease and Related Disorders*; and *Journal of Religion and Health*.

## CHRISTOPHER M. CALLAHAN, MD, FACP



Dr. Callahan graduated from St. Louis University School of Medicine in 1985. He completed his Internal Medicine residency at Baylor

College of Medicine in 1988 and completed a fellowship in Health Services Research at the Indiana University School of Medicine in 1991. He has a Certificate of Added Qualifications in Geriatric Medicine and his clinical practice focuses on the care for older adults with depression and dementia. He is a Research Scientist in the Regenstrief Institute, Inc and the founding Director of the Indiana University Center for Aging Research. He is the Cornelius and Yvonne Pettinga Professor in Aging Research. In 1999-2000 he was a Visiting Scholar in the History and Psychopathology Research Program in the Department of Psychiatry at Cambridge University in the United Kingdom. During this sabbatical, he co-authored the book "Reinventing Depression: A History of the Treatment of Depression in Primary Care" (Oxford University Press).

Dr. Callahan is a 1996 recipient of a Paul B. Beeson Physician Faculty Scholar in Aging Award. His research has been supported by the John A. Hartford Foundation, Inc, the Agency for Healthcare Research and Quality, the National Institute on Aging, and the National Institute on Mental Health. He is the recipient of a Mid-Career Research Mentorship Award from the Society of General Internal Medicine in 2006 and the National Award for Career Achievement and Contribution to Clinical and Translational Science from the Society for Clinical and Translational Sciences in 2012. He has served on numerous national committees exploring strategies to improve the care of older adults.

## SPEAKERS (CONTINUED)

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### LEISA R. EASOM, PHD, RN



Leisa R. Easom, Ph.D., RN is the Executive Director of the Rosalynn Carter Institute for Caregiving (RCI) and Pope Eminent Scholar at

Georgia Southwestern State University (GSW). The mission of the RCI is to establish local, state, national and international partnerships committed to building quality long-term, home and community-based services for caregivers in the promotion of caregiver health, skills, and resilience. Dr. Easom was a Professor of Nursing and served as the Chair in the GSW School of Nursing from 2007-2010. Prior to that, she served as the Program Coordinator of the RN-BSN program at Macon State College in Macon, Georgia. She has served as an adjunct professor for the Clinical Nurse Leader graduate program at the Medical College of Georgia. Dr. Easom has been a Registered Nurse for over 30 years and devoted much of her nursing practice to addressing the mental and physical health needs of the older adult population.

Dr. Easom completed her doctoral degree in nursing at the Medical College of Georgia in 2003. Post-doctoral education included end-of-life training. Certified in gerontology, Dr. Easom focuses her program of research on caregivers, end-of-life issues, aging, and health promotion in rural areas of the United States. She has served as the principal investigator on numerous projects related to aging, caregiving, and nursing with results being published in scientific journals.

She has been the recipient of many awards including Teacher of the Year Award at GSW and was selected as a Helene Fuld Scholar recipient for the American Association of Colleges of Nursing (AACN) Leadership program. Dr. Easom serves on many collegiate committees and, additionally serves on the Medical Assisting Board for South Georgia Technical College,

on the Caregiving Advisory Panel for the U. S. Administration on Aging, the Carter Center Task Force for Mental Health and is a member of the American Society on Aging, Gerontological Society of Aging, and National League for Nursing.

### LAURA N. GITLIN, PHD



Dr. Laura N. Gitlin, an applied research sociologist, is nationally and internationally recognized in the areas of nonpharmacologic

approaches in dementia care, family caregiving, functional disability and aging in place. She is a well-funded researcher, having received continuous research and training grants from both federal agencies and private foundations, including the Alzheimer's Association and the National Institutes of Health for over 25 years. Her programs of research include understanding adaptive processes in old age including use of assistive devices and environmental modifications, psychosocial-environmental approaches to helping older people with physical frailty age in place, nonpharmacologic approaches to enhancing quality of life of persons with dementia and their family caregivers, mental health disparities in older African Americans and depression treatments, and translating and implementing evidence-based interventions for family caregivers, individuals with dementia, and older adults with functional difficulties. Dr. Gitlin recently joined the Johns Hopkins University School of Nursing as a Professor in the Department of Health Systems and Outcomes with joint appointments in the Department of Psychiatry and Division of Geriatrics and Gerontology, School of Medicine. She is developing with colleagues the Center for Innovative Care in Aging, an interprofessional and interdivisional initiative to examine issues related to developing, testing and implementing health promoting interventions for older adults and their

families and generate novel interventions with translational potential. Dr. Gitlin is the recipient of numerous awards including the 2009 Eastern Pennsylvania Geriatric Society, Charles Ewing Presidential Award for outstanding contribution to geriatric care; the 2010 United Way Champion Impact Award for Healthy Aging at Home, the 2010 National Institute of Senior Centers Award with Center in the Park, the 2010 MetLife Award for translating the Skills<sub>2</sub>Care™ Program (a dementia caregiver intervention program) with Fox Rehabilitation (a home health agency); and the 2011 John Mackey Award for Excellence in Dementia Care, from Johns Hopkins University.

### KAREN B. HIRSCHMAN, PHD, MSW



Dr. Hirschman is a Research Assistant Professor at the University of Pennsylvania (Penn) School of Nursing, and faculty of the

NewCourtland Center for Transitions and Health. Dr. Hirschman joined the Transitional Care Model team at Penn in 2004, collaborating with Dr. Mary Naylor and colleagues, expanding application of the TCM to hospitalized older adults with cognitive impairment and their family caregivers—a public-private partnership funded by the National Institute on Aging (NIA) and the Marian S. Ware Alzheimer's Disease Program at Penn. More recently, the TCM team is exploring implementation of the TCM in primary care practices, co-sponsored by the Gordon and Betty Moore Foundation, the Jonas Center for Nursing Excellence and the Rita and Alex Hillman Foundation. With a background in social work and social welfare and training in age-related neurodegenerative diseases, Dr. Hirschman brings a unique multidisciplinary approach to her research, focusing on transitions in health and health care, decision making, advance care planning, caregiver burden

and end-of-life care, with a specific emphasis on individuals with cognitive impairments and their family members. She has received funding from the NIA and the Alzheimer's Association.

Dr. Hirschman is a member of the National Association of Social Workers and the Gerontological Society of America, currently serving as the Convener for the Hospice, Palliative and End of Life Care Interest Group. Dr. Hirschman completed a postdoctoral fellowship in Age-Related Neurodegenerative Diseases at Penn Medicine, Center for Neurodegenerative Disease Research (CNDP). She earned her doctorate in Social Welfare and master's degree in Social Work at the University of Pennsylvania.

### SUSAN MCCURRY, PHD



Dr. Susan McCurry is Research Professor in the Department of Psychosocial and Community Health and Adjunct Research Professor in Psychiatry and Behavioral Sciences. She received her doctorate in clinical psychology at University of Nevada, Reno in 1991 and has been at the University of Washington since that time. Her clinical and research interests focus on various aspects of gerontology and geriatrics, particularly helping family and professional caregivers manage behavioral challenges in persons with dementia. She is a fellow in the Gerontological Society of America, and has been co-investigator on 25 Federal, State, and foundation grants related to aging and dementia. Dr. McCurry has also authored over 100 professional publications, including two books designed to help family caregivers and health care professionals provide more effective and compassionate care to cognitively impaired individuals. Her ongoing research includes (1) assessment and management of sleep

disturbances in older adults with dementia or other co-morbid medical conditions such as chronic pain; (2) development and evaluation of training programs for family and professional staff caring for persons with dementia; and (3) examination of the environmental, behavioral, and psychosocial factors associated with cognitive decline.

### MARY S. MITTELMAN, DRPH



Mary S. Mittelman is an epidemiologist who has been evaluating psychosocial interventions for people with cognitive impairment and their family members for more than two decades. She received a Dr.P.H. in psychiatric epidemiology and an M.S. in biostatistics from Columbia University School of Public Health. Dr. Mittelman is Director of the Psychosocial Research and Support Program of the NYU Comprehensive Center on Brain Aging and Research Professor in the NYU Langone Medical Center Department of Psychiatry. For more than 20 years she was Principal Investigator of the NYU-Spouse Caregiver Intervention (NYUCI) study, first funded by the NIH in 1987.

Publications from the study of the NYUCI provided evidence that counseling and support for spouse caregivers and their families can have a major impact on the time a person with AD can remain at home and on the well-being of the family caregiver as well. Other publications demonstrate the long-term effectiveness of counseling and support for caregivers in reducing symptoms of depression and the severity of their reactions to the behavior of their family members with dementia and in maintaining caregiver physical health. More recent publications show that the mechanism through which the intervention achieves these improvements in caregiver well-being is by improving the support and assistance from family members and friends and that the interventions effects

on caregiver well-being lasted through nursing home placement and death of the person with dementia.

The NYU Caregiver Intervention has won many awards, including an award from the National Alliance for Caregiving and the MetLife Foundation in 2010 and the first global award for Alzheimer's psychosocial research from Alzheimer's Disease International/ Fondation Mederic Alzheimer (March 2009). Other awards include the annual New York City Family Caregiver Coalition award in 2009, the Maggie Kuhn Award from Presbyterian Senior Services for her work to help older adults and the Aging, the Rosalynn Carter Caregiver Leadership Award.

In the past few years, Dr. Mittelman has made a commitment to disseminate research findings to both health care providers and the community at large and to collaborate with community organizations to implement evidence-based psychosocial interventions in community settings. She has collaborated with organizations funded by the United States Administration on Aging, the Rosalynn Carter Institute and the Department of Veterans Affairs, providing assistance for translations of the NYU Caregiver Intervention in communities around the United States. With her colleagues, she has written several books for caregivers and health care professionals, including *Counseling the Alzheimer's Caregiver: A Resource for Health Care Professionals*, published in 2003 by the American Medical Association.

More recently, Dr Mittelman has been evaluating and developing interventions that include the person with dementia together with the caregiver, most notably a chorus, *The Unforgettables*, which has been rehearsing and performing in New York City since June 2011.

# ATTENDEES

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## **Michelle Barclay, MA**

Vice President of Programs  
Alzheimer's Association  
Minnesota-North Dakota  
michelle.barclay@alz.org

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

Senior Research Scientist and  
Vice President for Research  
Margaret Blenkner Research Institute  
Benjamin Rose Institute on Aging  
dbass@benrose.org

## **Cynthia Bens**

Director, Public Policy  
Alliance for Aging Research  
cbens@agingresearch.org

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

Deputy Director  
National Institute on Aging,  
National Institutes of Health  
mbernard@nia.nih.gov

## **Salli Bollin, MSW**

Executive Director  
Alzheimer's Association,  
Northwest Ohio Chapter  
salli.bollin@alz.org

## **Kerry Branick**

Public Health Analyst  
Office of State and Community Programs  
Centers for Medicare and Medicaid  
kerry.branick@cms.hhs.gov

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

Associate Professor and Gerontological  
Nurse Practitioner  
Department of Biobehavioral Health Science  
University of Illinois, Urbana  
sburgener@illinois.edu

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

Director, Indiana University Center for  
Aging Research  
Indiana University School of Medicine,  
Regenstrief Institute, Inc.  
ccallaha@iupui.edu

## **Greg Case, MA**

Director, Office of Supportive and  
Caregiver Services  
Administration on Aging  
Administration for Community Living  
Department of Health and Human Services  
greg.case@aoa.hhs.gov

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

Executive Vice President  
Alzheimer's Association, California  
Southland Chapter  
debra.cherry@alz.org

## **Lindsay Clarke**

Director, Health Programs  
Alliance for Aging Research  
lclarke@agingresearch.org

## **Barney Cohen, PhD**

Director, Committee on Population  
National Academy of Sciences  
bcohen@nas.edu

## **Lucy Do**

Intern  
Alliance for Aging Research

## **Leisa Easom, PhD, RN**

Executive Director  
Rosalynn Carter Institute for Caregiving  
Georgia Southwestern State University  
leisa.easom@gsw.edu

## **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  
gary\_epstein-lubow\_md@brown.edu

## **Lynn Feinberg**

Senior Strategic Policy Advisor  
AARP Public Policy Institute  
lfeinberg@aarp.org

## **Rachel Feldman**

Policy Associate  
National Association of States United for  
Aging and Disabilities (NASUAD)  
rfeldman@nasuad.org

## **Laura N. Gitlin, PhD**

Professor, Department of Health Systems  
and Outcomes  
School of Nursing  
Director, Center for Innovative Care in Aging  
Johns Hopkins University  
lgitlin1@jhu.edu

## **Elizabeth Gould, MSW, LCSW**

Co-Director, ADSSP National Resource Center  
Alzheimer's Association  
elizabeth.gould@alz.org

## **Kathy Greenlee**

Administrator, Administration for  
Community Living  
Assistant Secretary for Aging  
Department of Health and Human Services  
kathy.greenlee@aoa.hhs.gov

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

Associate Professor, Department of  
Psychiatry and Behavioral Sciences  
Director, Duke Center for Aging Family  
Support Program  
Director, Duke Employee Elder Care  
Consultation Service  
Education Director, Bryan Alzheimer's  
Disease Research Center  
lisa.gwyther@duke.edu

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

Research Assistant Professor  
University of Pennsylvania  
School of Nursing  
hirschk@nursing.upenn.edu

## **Mollie Howerton, PhD, MPH**

Health Insurance Specialist  
Centers for Medicare and Medicaid Services  
mollie.howerton@cms.hhs.gov

## **Beth Kallmyer**

Vice President, Constituent Services  
Alzheimer's Association  
beth.kallmyer@alz.org

**Kathleen Kelly, MPA**

Executive Director  
National Center on Caregiving  
Family Caregiver Alliance  
kkelly@caregiver.org

**Mark E. Kunik, MD, MPH**

Associate Director  
Houston VA Health Services Research  
and Development Center of Excellence  
Associate Director for Research Training,  
South Central MIRECC  
Professor, Menninger Department of  
Psychiatry and Behavioral Sciences  
Baylor College of Medicine  
mkunik@bcm.edu

**Laura Lawrence, MHSA, MBA, LTCP**

Director, Office of Nutrition and Health  
Promotion Programs  
Administration on Aging  
Administration for Community Living  
Department of Health and Human Services  
laura.lawrence@hhs.gov

**Shari M. Ling, MD**

Deputy Chief Medical Officer  
Centers for Medicare and Medicaid Services  
shari.ling@cms.hhs.gov

**Johnalyn D. Lyles, PhD**

Technical Lead, EHR Incentive  
Program Appeals  
Centers for Medicare and Medicaid Services  
johnalyn.lyles@cms.hhs.gov

**Sandy Markwood, MA**

Chief Executive Officer  
National Association of Area Agencies  
on Aging (N4A)  
smarkwood@n4a.org

**Michael Maroni**

Programs & Policy Assistant  
Alliance for Aging Research  
mmaroni@agingresearch.org

**Katie Maslow, MSW**

Scholar-in-Residence  
Keck Center, Institute of Medicine  
kmaslow@nas.edu

**Susan McCurry, PhD**

Research Professor  
Psychosocial and Community Health  
University of Washington  
smccurry@u.washington.edu

**Jessica McIlvane, PhD**

Health Science Policy Analyst  
National Institute of Nursing Research,  
National Institutes of Health  
mcilvanejm@mail.nih.gov

**Mary S. Mittelman, DrPH**

Research Professor, Department of Psychiatry  
NYU, Comprehensive Center on  
Brain Aging  
mary.mittelman@nyumc.org

**Raksha Anand Mudar, PhD, CCC-SLP**

Assistant Professor, Department of  
Speech and Hearing Science  
Center on Health, Aging and Disability  
College of Applied Health Science  
University of Illinois, Urbana-Champaign  
raksha@illinois.edu

**Lis Nielsen, PhD**

Chief, Individual Behavioral  
Processes Branch  
Division of Behavioral and Social Research  
National Institute on Aging, National  
Institutes of Health  
nielsenli@nia.nih.gov

**Susan Peschin**

Chief Operating Officer  
Alliance for Aging Research  
speschin@agingresearch.org

**Nina Silverberg, PhD**

Assistant Director  
Alzheimer's Disease Centers Program  
Division of Neuroscience  
National Institute on Aging, National  
Institutes of Health  
silverbergn@mail.nih.gov

**Shannon Skowronski, MPH, MSW**

Aging Services Program Specialist  
Office of Nutrition and Health  
Promotion Programs  
Administration on Aging  
Administration for Community Living  
Department of Health and Human Services  
shannon.skowronski@aoa.hhs.gov

**Eric Sokol**

Vice President, Public Policy  
Alzheimer's Foundation of America  
esokol@alzfdn.org

**Alan B. Stevens, PhD**

Director, Center for Applied Health Research  
Scott and White Healthcare  
astevens@swmail.sw.org

**Richard Suzman, PhD**

Director, Behavioral and  
Social Research Program  
National Institute on Aging, NIH  
suzmanr@nia.nih.gov

**Jane Tilly, DrPH**

Senior Analyst  
Office of Supportive and Caregiver Services  
Administration on Aging  
Currently on detail to:  
Office of the Assistant Secretary for  
Planning and Evaluation  
Department of Health and Human Services  
jane.tilly@aoa.hhs.gov

**Sandra Timmermann, EdD**

Vice President and Director  
MetLife Mature Market Institute  
stimmermann@metlife.com

**Edwin L. Walker**

Deputy Assistant Secretary  
Administration on Aging  
Administration for Community Living  
Department of Health and Human Services  
edwin.walker@aoa.hhs.gov

**Michelle M. Washko, PhD**

Policy Analyst  
Office of Policy Analysis and Development  
Center for Disability and Aging Policy  
Administration for Community Living  
Department of Health and Human Services  
michelle.washko@aoa.hhs.gov

**Carol J. Whitlatch, PhD**

Assistant Director  
Margaret Blenkner Research Institute  
Benjamin Rose Institute on Aging  
cwhitlat@benrose.org

**Nancy L. Wilson, LCSW**

Associate Professor  
Department of Medicine-Geriatrics  
Huffington Center on Aging  
Baylor College of Medicine  
nwilson@bcm.edu

**Debbie Zeldow**

Executive Vice President  
Alliance for Aging Research  
dzeldow@agingresearch.org

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